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Factors that Influence Marital Satisfaction in Couples Raising a Child with Cerebral Palsy

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FACTORS THAT INFLUENCE MARITAL SATISFACTION IN COUPLES RAISING A CHILD WITH CEREBRAL PALSY

by

Sarah L. Stoker

A thesis submitted in partial fulfillment
of the requirements for the degree

of

MASTER OF SCIENCE

in

Family, Consumer, and Human Development

ABSTRACT

Factors That Influence Marital Satisfaction in
Couples Raising a Child with Cerebral Palsy

by

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Utah State University, 2004

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Department: Family, Consumer, and Human Development

This study examined factors that influence marital satisfaction in couples raising a child with cerebral palsy. The theoretical frameworks for this study were drawn from family systems theory and the social ecology model.

Twenty-eight married couples raising a child between the ages of 3-17 years, with a diagnosis of cerebral palsy, comprised the sample for this study. Participants were classified as raising a child who is mildly/moderately or severely impaired by cerebral palsy. Participants were recruited through referrals of professionals working in local organizations that provide services and support for persons with disabilities and their families.

Data were analyzed using correlation, and two-tailed *t* tests. Analysis was based on the following research question: To what extent is the marital satisfaction of couples raising a child between the ages of 3-17 years with a diagnosis of cerebral palsy influenced by couple cohesion and adaptability, individual coping style, and sources of family and community support?

Statistical analysis revealed that for most couples, cohesion and adaptability as measured by FACES II were associated with higher levels of marital satisfaction. For wives, Coping Style I: Maintaining Family Interaction, Cooperation, and an Optimistic Definition of the Situation as measured by the Coping Health Inventory for Parents was found to be positively associated with their marital satisfaction. Husband's coping style was not found to be significantly and positively correlated with their level of marital satisfaction. Analysis of family and community support were not performed due to low alpha reliabilities for both husbands and wives on the Family Support Scale, and the failure of its subscales to hold together. Bivariate correlations of the severity of the child's disability with the parent's level of marital satisfaction were nonsignificant for both husbands and wives.

Findings from this study support the notion that marital satisfaction in couples with a child with cerebral palsy may be enhanced by couple cohesion and adaptability. Wives who cope by strengthening family life and relationships, and who have a positive outlook on life may also experience greater levels of marital satisfaction. Future research with larger samples of couples is needed to replicate these findings.

(145 pages)

DEDICATION

To the couples that participated in this study, for your generosity in sharing your experiences of raising a child with cerebral palsy. Your cooperation, honesty, and willingness to give of your time are greatly appreciated.

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I gratefully recognize the mentoring and wisdom of Dr. Kathleen W. Piercy, whose perceptive ideas guided me, whose constant belief in this project kept me going. Your advice, support, and continued encouragement and assistance will never be forgotten. Your friendship will always be treasured.

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Special thanks go out to my family for their love, encouragement, support, and patience.

Sarah L. Stoker

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CHAPTER I

INTRODUCTION

Raising a child with a physical and intellectual disability is an extraordinary event from which no parent is immune, and most are generally ill prepared (Seligman & Darling, 1997). Most expectant mothers and fathers fantasize about their all-around gymnast or curly haired mathematician, while in the back of their mind secretly dreading the possibility that "something might go wrong," and if it does, "what effect will it have on my marriage?"

In personal communication with four couples raising a child with a disability, I asked the question: *"How has raising a child with a disability affected your marriage?"*

> "Unfortunately, my husband and I divorced. I have read that this is very common. I worry that my daughter feels responsible for our divorce."
>
> \- Mother of an adult daughter with spina bifida

> "A ton. I am a stay at home mom, so that really helps. We try to make time for each other, go out to dinner or something, but it is very hard to leave him with a babysitter."
>
> \- Mother of a pre-teen son with autism

> "We have our ups and downs, just like any other couple. In the beginning, we would fight a lot about taking care of our son. I felt frustrated. I did not know how to help him. My wife had a system down; it seemed that when I tried to help, I just messed up the system. I love my son, I feel bad that I felt so awkward."
>
> \- Father of a school-aged son with Down syndrome

> "It is very hard to stay together. We have to work at it everyday. We are committed to each other, but raising our daughter is definitely the biggest trial in our marriage. I am grateful for my husband who recognizes that we need to take

> things a day at a time and be grateful for the opportunity to raise our daughter. It really helps to have his support. He really is amazing, I am grateful for his support. He is able to relate to her in that special father-daughter way. Her face lights up when he comes home from work."
>
> \- Mother of a toddler daughter with cerebral palsy

Statement of the Problem

From the preceding glimpses into these couples' marriages, it is apparent that raising a child with a disability is truly a compelling, life altering experience, which does influence the marital relationship in diverse ways.

Despite the prevalence of research literature on childhood disability, little attention has been given to the topic of marital satisfaction in couples raising a child with a disability. A review of the existing literature pertaining to marital satisfaction in couples raising a child with a disability was mixed (Demarle & Le Roux, 2001; Ehrenkrantz, Miller, Vemberg, & Fox, 2001; Gabel, McDowell, & Cerreto, 1983; Mullins, 1987). For example, Olsen (1999) found that in some couples, raising a child with a disability exacerbated latent marital problems, while in other couples raising a child with a disability marital commitment was strengthened.

Smith, Oliver, and Innocenti (2001) found that couples raising a child with a disability were more likely than couples raising a typically developing child to feel drained and less able to cope with other areas of family life, such as issues that may arise in the marital relationship. Harris (1983) stated that couples raising a child with a disability face many unique challenges as they strive to maintain day-to-day functioning. Specifically, the child's disability can become a commanding presence and constant source of stress in the couple's lives, leaving little time for nurturing the marital relationship.

Conversely, Green (2002), who is the parent of a child with cerebral palsy, credits her husband's support as a fundamental reason for their daughter's success, and refers to him as her partner on her journey. McDonald (1995), who is also the parent of a child with a disability, stated that the experience of raising a child with a disability has strengthened her marriage.

It is important to understand the factors that influence marital satisfaction in couples raising a child with a disability. The health and well being of each spouse, as well as the couple, family integrity, parental perceptions of the child, and styles of parent-child interaction are all influenced by marital satisfaction (Seligman & Darling, 1997; Smith et al., 2001).

Purpose of the Study

The purpose of researching the factors that influence marital satisfaction in couples raising a child with a disability was to identify specific factors that contribute to marital satisfaction, in order to assist parents and those who work with families of children with disabilities to understand the implications of childhood disability on the marital relationship. Specifically, this study examined couple cohesion and adaptability, individual coping style, and sources of family and community support. By examining these issues through a family systems and social systems perspective, factors associated with higher levels of marital satisfaction in couples raising a child with a disability, as well as areas of needed support, were identified.

While it would have been ideal to look at all types of childhood disabilities and marital satisfaction, such an undertaking was not within the scope of this study. Rather, this study focused on couples raising a child between the ages of 3-17 years with a diagnosis of cerebral palsy.

Cerebral Palsy

Cerebral means of the brain and palsy means lack of muscle control. Thus, cerebral palsy is a medical term used to describe a nonprogressive but not unchanging group of disorders affecting control of muscle movement, coordination, and body posture due to an insult, anomaly, defect or lesion of the developing brain, which interferes with messages from the brain to the body, and from the body to the brain, often accompanied by some degree of mental retardation (Hutchison, 1995; Kuban & Leviton, 1994; Pellegrino, 1997).

Brain development begins early in pregnancy and continues to about age twenty. Any damage to the developing brain before, during or shortly after birth may result in cerebral palsy. Any damage to the brain after three years of ages is not considered a cause of cerebral palsy (Jarvis & Hey, 1984). The definitive cause of cerebral palsy has not been identified; however, cerebral palsy has been linked to accidents that occurred before, during, or shortly after birth that result in brain injury, as well as the health history of both the mother and child (Kuban & Leviton, 1994).

The effects of cerebral palsy vary from individual to individual. Mild or moderate cerebral palsy may result in slightly awkward movement, whereas severe cerebral palsy may affect the entire body, resulting in almost no muscle control. Cerebral palsy is not hereditary, contagious, life threatening, or progressive, although the effects of cerebral palsy may improve, worsen, or remain unchanged over time (Hutchison, 1995). According to the United Cerebral Palsy organization (2002), cerebral palsy affects roughly equal numbers of men and women, and approximately 5,000 children nationally are diagnosed with cerebral palsy each year.

Depending on which area(s) of the brain have been damaged, one or more of the following may occur: mental retardation, muscle tightness, involuntary movement, and difficulty with gross and fine motor skills (Kuban & Leviton, 1994). Cerebral palsy is classified according to the degree of mental retardation, type of movement disorder, and by the number of limbs affected (Jarvis & Hey, 1984).

These major classifications include the following types of cerebral palsy. Spastic cerebral palsy is the most common type, occurring in approximately 50% of cases. Spastic cerebral palsy is caused by damage to the motor cortex, which results in the muscles being too tight, which in turn limits movement. Quadriparesis refers to a condition in which all four limbs are affected. Spastic Diplegia refers to either the arms or legs being affected, whereas Hemiparesis refers to one side of the body being affected (Back, 1999; Jarvis & Hey, 1984; Pellegrino, 1997).

Choreo-Athetoid cerebral palsy, which occurs in approximately 20% of cases, results in the muscles fluctuating between being too tight and too weak. Choreo-Athetoid cerebral palsy is caused by damage to the basal ganglia or cerebellum, which results in difficulty controlling and coordinating muscle movements such as: walking, speech, and reaching for and grasping objects. Involuntary movements are typical of Choreo-Athetoid cerebral palsy; these include: (a) athetosis, slow, writhing movements, particularly in the hands and face; (b) ataxia, unsteady walking and balance problems; (c) chorea, jerky movements of the head, arms, or legs; and (d) dystonia - twisting movements and postures of the trunk or limbs (Back, 1999; Jarvis & Hey, 1984; Pellegrino, 1997).

Mixed cerebral palsy, which occurs in approximately 30% of cases, results in the muscles being affected in any combination of the above. Hypotonia (involuntary movement) is considered the marker movement, with spasticity increasing as the child grows (Back, 1999; Jarvis & Hey, 1984; Pellegrino, 1997).

Causes of Cerebral Palsy

Factors during pregnancy, that may cause cerebral palsy, include, but are not limited to, maternal bleeding and severe proteinuria in the last trimester, diabetes, high blood pressure, hyperthyroidism, infections, poor nutrition, and exposure to toxic substance. Fetal factors include, but are not limited to, mutations of the developing brain, nervous system malformations, and damaged placenta (Kuban & Leviton, 1994; Pharoah, Platt, & Cooke, 1996).

Factors during labor and delivery that may cause cerebral palsy include, but are not limited to, (a) prolonged rupture of the amniotic membranes which leads to fetal infection, (b) seizures in the newborn, (c) complicated labor and delivery, (d) abnormal positioning of the baby, such as breech presentation, (e) premature delivery, (f) low birth weight, and (g) multiple births (Kuban & Leviton, 1994; Pharoah et al., 1996).

Factors during early childhood that may cause cerebral palsy, include, but are not limited to brain damage due to infection such as meningitis, brain hemorrhages, head injury following a fall, accidents, abuse, and, seizures that cause a lack of oxygen (Kuban & Leviton, 1994; Pharoah et al., 1996). Overall, cerebral palsy is the result of a hypoxic episode affecting the developing brain (Pellegrino, 1997).

Symptoms of Cerebral Palsy

Parents often are the first to notice that their infant is slower than normal to reach certain developmental milestones, such as feeding, rolling over, sitting up, crawling, standing, walking and talking (Hutchison, 1995). According to Jarvis and Hey (1984) and Kuban and Leviton (1994), during the first months and years of life, a child with cerebral palsy may demonstrate some or all of the following symptoms that range from mild to severe: (a) abnormal muscle tone that changes from floppy to very stiff, (b) trembling of the arms and legs, (c) body twitching, (d) abnormal posture and reflexes, including asymmetry of movement, (e) holding his or her hand in tight fists, (f) seizures/spasms, (g) staring spells or eye fluttering, (h) lethargy, (i) irritability, (j) high-pitched crying, (k) hyperactivity, (l) visual, hearing, and speech problems, and (m) learning disabilities and mental impairment.

In addition to mental impairment and difficulty controlling the muscles in their arms and legs, children with cerebral palsy have difficulty sucking and swallowing, and controlling their tongue, mouth, lips, jaw, and breath flow, and may be prone to drooling. Feeding problems are often the first indicator of developmental problems. Children with cerebral palsy feed poorly, with their tongue forcefully pushing food out of their mouth. This is a great concern because lack of food can lead to malnutrition, as well as poor growth and development (Jarvis & Hey, 1984; Pellegrino, 1997).

Diagnosing Cerebral Palsy

A diagnosis of severe cerebral palsy can be made by most developmental physical therapists by four months of age. By the time a child is nine months old a diagnosis should be made (P. Boyle, personal communication, June 16, 2003). However, according to Evans, Evans, and Alberman (1990) a diagnosis of cerebral palsy is unlikely to be made until the child's progress is observed over a period of time, up to three years, and other conditions have been ruled out. The delay in diagnosis has to do with the ability of a child's central nervous system to recover completely or partially after an injury has occurred. Generally, however, a child's central nervous system has stabilized by three years of age (Jarvis & Hey, 1984).

Treatment and Management of Cerebral Palsy

According to Evans and associates (1990), children with cerebral palsy need to be monitored by an interdisciplinary team of professionals with specialties in different areas. At a minimum, the professional team should consist of a physical therapist, occupational therapist, speech-language pathologist, and kinesiologist, who will work to help the child improve posture and movement (Pellegrino, 1997). Other members of the professional team may include, but are not limited to, an audiologist, dentist, ear, nose and throat surgeon, early childhood educator, dietician, neonatologist, neurologist, neurosurgeon, ophthalmologist, orthopedic surgeon, pediatrician, podiatrist, psychiatrist, rehabilitation technologist, social worker, special childhood educator, and urologist (Back, 1999; Pellegrino).

Enormous numbers of aids and adaptive equipment are available for children with cerebral palsy. These can include casts, communication devices, orthotics, splints, walker, wheelchair, and daily living aids such as special grips for holding onto small objects such as a fork (Back, 1999; Pellegrino, 1997). Medication is sometimes prescribed for symptom relief and surgery is sometimes necessary to reduce spastic movement and correct deformities (Jarvis & Hey, 1984).

Evans and colleagues (1990) stated that educational support is vital, and all children with cerebral palsy should have an Individualized Education Plan (IEP). However, not all children with cerebral palsy are eligible for special education, and most children with cerebral palsy receive an integrated education, so it is recommended that children with cerebral palsy should be enrolled at an early age in an early intervention program and have an Individualized Family Service Plan (IFSP).

Outcomes for Children with Cerebral Palsy

In some instances, individuals with cerebral palsy enjoy university education, rewarding careers, fulfilling social lives, and parenthood. However, having cerebral palsy does not make one immune to other conditions, and individuals with cerebral palsy are as likely as anyone to contract any of a multitude of diseases. In addition, the mental and physical challenges often associated with cerebral palsy including lower cognition, increased spastic movement, fatigue, loss of strength, or declining mobility may intensify and become more of a hindrance with age (Back, 1999). Thus, unfortunately, the majority of children with cerebral palsy do not lead fulfilling lives. Many die, while others face discrimination because of their disability. Many start out with functional abilities, but due to their abnormal movements, their fight against gravity results in continued disability and pain (P. Boyle, personal communication, June 16, 2003).

Outcomes for Parents of Children with Cerebral Palsy

While much has been studied regarding childhood disabilities and the impact of raising a child with a disability on the family system, little attention has been paid to the marital system (Lyon & Lyon, 1991). The aim of this study was to shed some light on this understudied area of family and human development by examining factors considered important in marriage, namely couple cohesion and adaptability, individual coping style, and sources of family and community support. A better understanding of how these factors affect marital satisfaction in couples raising a child with cerebral palsy is needed.

CHAPTER II

LITERATURE REVIEW

Theoretical Frameworks

The theoretical frameworks for this study were drawn from two bodies of literature. The first body of literature focuses on the affective closeness between husband and wife, which is important for understanding the interaction among couples and families. The second body of literature focuses on social support and professional helpers which often times can be mediating factors in helping couples to meet the stressful demands of raising a child with a disability, and are important for understanding the relationship between the family and the community. Specifically, Family Systems Theory, and the Social Ecology Model were selected after a careful review of factors affecting marital satisfaction under stressful circumstances.

Family Systems Theory

Family Systems Theory (Bowen, 1978) is based on the interactive nature of the family. This theory emphasizes that a family is more than the sum of its parts. Family Systems Theory posits that it is within the family that individuals are simultaneously influencing and being influenced by each other and their environment in a continuous sequence of interaction based on internal and external forces (Klein & White, 1996).

Internal forces are characteristics that are unique to each family, and may or may not be affected by factors in the community (Broderick, 1993). Thus, the functioning of family systems is based primarily on internal forces, such as family cohesiveness, "the emotional bonding that members have toward one another," (Olson, 2000, p.145) and adaptability, "the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress" (Olson, Portner, & Bell, 1989, p. 1). For example, a family with high levels of cohesiveness and high levels of adaptability would work together, viewing the event of raising a child with cerebral palsy as a family event. Conversely, a family with low levels of cohesiveness and adaptability may view the event of raising a child with cerebral palsy as an individual event, and its members may be less responsive to change. In most familial subsystems, internal forces such as cohesion and adaptability are strongly related to functioning and crisis management (Broderick).

Family function is a product of family interaction. To carry out functions successfully requires considerable interdependence between the family and its extra-familial networks (Tarakeshwar & Pargament, 2001). Kozub (2001) stated that external forces possibly are the most permanent component of the family system, and can play an important role in shaping the families' ideological style, patterns of interaction, and level of functioning. Broderick (1993) found that in most familial subsystems, external forces are also highly related to family functioning and crisis management.

Further, Tarakeshwar and Pargament (2001) found that a family's response to a significant event, such as raising a child with a disability, and its coping methods are influenced by a combination of their cultural beliefs, ethnicity, religiosity, values, norms, socioeconomic status, history, expectations, and stage in the family life cycle. These entities also were found to influence a family's trust and use of professional caregivers and institutions.

Family systems theory also posits that each individual within a family is a member of a unique social system to which he or she must learn to interact. Individual actions and ability to adapt are governed by the uniqueness of the family system, as well as personality. Often each member in a family system interacts with the other members so thoroughly that origin and result cannot be determined (Broderick, 1993).

Accordingly, family systems theory views family interactions as having a mutual influence on one another, in which what happens to one member usually affects every other member of the family. For example, when a child with cerebral palsy is born into a family, to a certain extent every member of the family has cerebral palsy (Seligman & Darling, 1997).

Family systems theory views the family unit as functioning best when individual family members strive to meet the needs of other members before their own (Kozub, 2001). Meeting needs can be accomplished by many means including (a) understanding and addressing psychological needs (Glidden, 1993), (b) being mindful of the economic situation, (c) maintaining education and work (Olsen, 1999), (d) helping with domestic responsibilities and healthcare, and (e) participating in recreational activities (Pearson & Sternberg, 1986).

Family systems theory also states that the family system works to preserve homeostasis, a state of equilibrium or system adaptation (Klein & White, 1996). Through following rules, fulfilling expectations, and maintaining boundaries, families are able to function successfully while meeting the needs of individual family members.

Thus, the physical, social, psychological, and emotional functioning of family members is extremely interdependent, with changes in one part of the system reverberating in other areas of the system (Broderick, 1993). Klein and White (1996) noted that an event or action by one member of the family system may change the actions of other family members, disrupting equilibrium. Each member of the family system responds either positively or negatively to the event or action, as the system strives to maintain and regain equilibrium. When the family system is not capable of maintaining and regaining equilibrium in response to a stressful event, individual family members and the family system may experience additional stress, which affects the physical and mental functioning of each individual member, and the family system as a whole (Klein & White).

Family systems theory recognizes subsystems such as marital, parental, sibling, and extended family. Family systems theory views family functioning as best understood by examining the relationships between family members. Specifically, Bradbury, Fincham, and Beach (2000) stated that the interpersonal processes, and exchanges within the marital dyad, as well as the milieus within which these exchanges occur, are the most important determinants of family functioning.

Social Ecology Model

Similar to family system theory, the social ecology model (Bronfenbrenner, 1979) delineates that a change in any area of the social ecological system will affect subparts of the system, creating a need for system adaptation (equilibrium). Specifically, the social ecology model is concerned with the family's interactions with various environments.

The social ecology model further asserts that the behavior of a family system can be influenced by a variety of internal and external events. Thus, the basic tenet of the social ecology model is the idea that if one wishes to change behavior, one must change the environment in which the behavior occurs (Bubolz & Sontag, 1993).

The social ecology model views the family system as nested within other social systems. The subsystems of the social ecology model include the microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1979). Mitchell (1983) has applied Bronfenbrenner's concepts of the social ecology model to the study of families raising a child with a disability. Mitchell's concepts are outlined below.

The core system is the microsystem, which constitutes the patterns of familial activities, responsibilities, and interpersonal relationships. The microsystem is comprised of the following relationships, mother-father, mother-child with a disability, mother-typically developing child, father-child with a disability, father-typically developing child, and child with a disability-typically developing child.

The microsystem functions in the mesosystem, which constitutes familial interactions with others outside of the family system. The mesosystem is comprised of the following relationships: medical and healthcare workers, extended family, friends/neighbors, work/recreation associates, early intervention programs, other parents, and the local community.

The mesosystem functions in the exosystem, which constitutes the environmental influences. The exosystem is comprised of the following systems: mass media, healthcare, social welfare, and education.

The final system, the macrosystem, constitutes the ideologies of the culture. The macrosystem includes the ethnic, cultural, religious, socioeconomic, economic and political values.

This study focused on several aspects of the social ecology model. In the microsystem, the wife/mother-husband/father dyad was the focus. While it would have been ideal to include all nuclear family relationships, such an undertaking was not within the scope of this study. In the mesosystem, sources of family support such as extended family and friends were the focus of study. In the exosystem, sources of community support such as medical and professional workers were examined. In the macrosystem, sources that aid in coping such as cultural and religious beliefs were the focal points.

Family systems theory and the social ecology model suggest that couples and families raising a child with a disability are remarkably complex, and that many factors influence their family life. These theories also posit that couples and families change in response to these influences as they progress through the lifecycle, and experience their child's developmental milestones (Bulboz & Sontag, 1993; Kozub, 2001).

Marital Satisfaction

Because marital satisfaction is an attribute of all marriages, it is important to understand the dynamics influencing marital satisfaction in couples in general. Studies of marital satisfaction revolve around the common themes of: commitment to the marriage including the expectation that the marriage will endure (Karney & Bradbury, 1995); appreciation of spouse (Levinger, 1994); trust (Fincham & Linfield, 1997); love and affection (Bradbury, Beach, Fincham, & Nelson, 1996; Kurdek, 1996), including emotional gratification (Karney & Bradbury); the ability to accept their spouse the way he or she is (Norton, 1983); support and encouragement, especially during crisis (Whiffen & Gotlib, 1989); good communication and listening skills (Baumeister & Leary, 1995); the desire to recreate and work together (Huston, 2000); willingness to sacrifice (Karney & Bradbury); a strong value system, with religion being the chief value (Booth, Johnson, Branaman, & Sica, 1995); problem solving techniques, and the ability to make decisions, and deal with conflict, stress, and crisis in a positive manner (Whiffen & Gotlib).

In regards to marital satisfaction in couples raising a child with a disability, Lyon and Lyon (1991) conducted an exhaustive review of the literature and concluded that the existing research regarding the impact a child with a disability has on marital satisfaction is sparse and contradictory. Patterson (1991) and Crnic, Friedrich, and Greenberg (1983) also found the subject to be understudied and contradictory. The following paragraph reviews the pertinent literature in this area to date.

For instance, both Green (2002), and McDonald (1995) reported high levels of marital satisfaction for couples raising a child with a disability. Conversely, Smith and associates (2001) reported that couples raising a child with a disability were more likely than couples raising a typically developing child to report lower levels of marital satisfaction. In addition, Joesch (1997) found that women whose children have cerebral palsy appear to have lower levels of marital satisfaction than mothers of typically developing children. However, Patterson (1991) reported no difference in marital satisfaction among couples raising a child with a disability when they were compared to couples raising a typically developing child.

To date, research has concluded the following in regards to marital satisfaction among couples raising a child with a disability. First, preexisting problems with marital satisfaction may be aggravated by the birth of a child with a disability (Seligman & Darling, 1997). Second, in some instances, a child with a disability may aggravate latent marital problems, while in other instances such a child may strengthen marital commitment (Olsen, 1999; Schwab, 1989). Third, many couples can cope successfully with the aid of family and community support (Greeff, 2000). Finally, marital dissatisfaction may result in divorce and single parenthood (Joesch, 1997).

Turnbull and Turnbull (1990) found that preexisting marital problems could be aggravated by the birth of a child with a disability. Specifically, they reported that couples with serious marital problems prior to the birth of their child with a disability were more likely to report a decrease in marital satisfaction after the birth of their child with a disability. Marsh (1992) also found that troubled marital relationships could be aggravated by the birth of a child with a disability. In their study of stress and coping by fathers of adolescents with mental retardation and fathers of adolescents without mental retardation, Houser and Seligman (1991) gave the example of a mother attending to the needs of her child with a disability before attending to the needs of her husband, causing him to feel abandoned. When this occurred, her husband respond by distancing himself from the family, causing her to feel alienated.

Ehrenkrantz and associates (2001) reported that in some instances raising a child with a disability aggravated pre-existing marital problems, while in others raising a child with a disability strengthen marital commitment. Olsen (1999) found that the intensity of caring for a child with a disability often has polar effects. For instance, in some couples the stress of raising a child with a disability can lead to feelings of entrapment and frustration, whereas in other couples feelings of affection and devotion are often engendered. Similarly, Kazak and Marvin (1984) found that parents raising a child with a disability reported comparable levels of marital satisfaction as parents of typically developing children. What leads some couples to do well under these circumstances, while others find their marriage foundering?

Greeff (2000) and Lichtenstein (1991) reported that many couples with a child with a disability cope successfully with the aid of family and community support. Dunst, Jenkins, and Trivette (1984) also reported that social support both directly and indirectly mediates couple, family, and child outcomes. Specifically, Demarle and Le Roux (2001) and Harris (1983) noted that couple's reactions to their child's disability varied depending on the couples' strengths and weaknesses, as well as their sources of family and community support. In particular, a couple's ability to adjust to the experience of raising a child with a disability is strongly influenced by their access to external resources such as caregivers and support groups.

The findings on divorce and single parenthood for couples raising a child with a disability are mixed, but in general, parents raising a child with a disability are not more likely to divorce than parents raising a typically developing child. However, raising a child with a disability may serve as a route to divorce (Seligman, 1999).

Mullins (1987) emphasized that raising a child with a disability can place extraordinary demands on the couple, and numerous couples have had their marriages destroyed or hampered under the strain. Gabel and associates (1983) found that raising a child with a disability is a frequently reported cause of feelings of marital dissatisfaction. Specifically, their research showed that higher rates of conflict, sexual difficulties, separation, and divorce were reported for couple's raising a child with a disability than for couples raising a typically developing child. In a study using a national sample of families, Hodapp (1995) reported that 20% of parents with a child with a disability were divorced or separated, as compared to 15.3% for parents of typically developing children.

Ideally, marriage and family serve as a haven from the world, with members draw on each other for support and security while facing unique challenges such as raising a child with a disability. Bradbury and colleagues (2000) stated that to the degree that the marriage is successful, the family is successful. Thus, research regarding the impact of raising a child with a disability on marital satisfaction is deserving of much more attention than it has thus far received.

Couple Cohesion and Adaptability

In all couple systems, cohesion and adaptability are strongly correlated with functioning and crisis management; this is true for couples raising typically developing children, as well as for couples raising a child with a disability (Seligman & Darling, 1997). Mirfin-Vetich, Bray and Watson (1997) suggested that cohesion and adaptability are sound determinants of a couple's ability to raise a child, especially when the child has a disability.

Olson, Russell, and Sprenkle (1980) developed the Circumplex Model of marital and family systems as a means of assessing cohesion and adaptability in couple and family systems that are experiencing stress due to any number and type of circumstances. Appendix D shows the Circumplex Model. The premise of the Circumplex Model is that the couple and family systems are more functional to the extent that the cohesion dimension and the adaptability dimension are balanced. This study focused on the couple system, using the couples' version of FACES II to measure cohesion and adaptability.

Cohesion

Cohesion is defined as the emotional closeness that couple members have toward one another. Specific concepts measured by the cohesion dimensions are: emotional bonding, boundaries, coalitions, time, space, friends, decision-making, interests, and recreation (Olson, 1991). The focal point of cohesion is how systems balance togetherness versus separateness (Olson, 2000).

There are four levels or types of cohesion ranging from low to high: disengaged, separated, connected, and very connected. The balanced areas (separated or connected) are usually considered optimal for couple functioning. The unbalanced areas (disengaged or very connected) are usually viewed as less favorable for couple functioning (Olson, 2000).

When cohesion is balanced (separated or connected), couple systems are apt to be most functional. Separated couple relationships have clearly defined boundaries, with members feeling both a sense of closeness and a sense of autonomy. Connected couple relationships also have clearly defined boundaries, with couple members feeling both a sense of emotional closeness and loyalty and an emphasis on spending time together (Olson, 1991).

Unbalanced systems (disengaged or very connected) are apt to be less functional for most couples. Disengaged relationships are based on emotional separateness and independence. Members of a couple are unable to rely on one another for support. Very connected relationships have an extreme amount of closeness and loyalty. Members of a couple are dependent on and reactive to each other (Seligman & Darling, 1997).

When cohesion is very low (disengaged), members of a couple have low levels of attachment and commitment to each other (Olson, 2000). Disengaged couples are characterized as having rigid boundaries. Furthermore, interactions in disengaged couples may be characterized by under involvement (Olson, 1991). Consequently, a child with a disability often feels free to initiate independent activity, but rarely feels loved.

When cohesion is very high (very connected), there is too much agreement within the couple and too little autonomy (Olson, 2000). Very connected couples are characterized as over-involved and over protective. Such a lack of autonomy can have harmful effects on children with disabilities by preventing them from participating in developmental activities (Olson, 1991). Olson and associates (1980) noted that couples that are very connected often have anxieties about letting go of their child.

Adaptability

Adaptability is defined as an individual's ability to change in response to a stressful situation (Olson, 2000). Specific concepts measured by the adaptability dimensions are leadership, negotiation styles, role relationships, and relationship rules. The focal point of adaptability is how systems balance change versus stability (Olson, 1991).

There are four levels or types of adaptability ranging from low to high: rigid, structured, flexible, and very flexible. The balanced areas (structured or flexible) are optimal for couple functioning. The unbalanced areas (rigid or very flexible) are viewed as less favorable for couple functioning (Olson, 2000).

When adaptability is balanced (structured or flexible), couple systems are apt to be most functional. Structured couple relationships have democratic leadership with some negotiation, roles are stable with some degree of sharing, there are few changes to rules, and rules are firmly enforced. Flexible relationships are based on egalitarian leadership, and employ a democratic approach to decision-making and change (Olson et al., 1980).

Unbalanced systems (rigid and very flexible) are apt to be less functional for most couples. Rigid relationships are based on one highly controlling individual who is in charge. Couple members are limited in negotiation, with strictly defined roles and unchanging rules. In contrast, very flexible relationships have erratic or limited leadership. Decisions are generally made on impulse, and are not thought out. Roles are ambiguous, often shifting from individual to individual (Olson et al., 1980).

When adaptability is very low (rigid), couple systems have low levels of coping skills (Olson, 2000). Rigid couples are characterized as lacking the ability to adjust in response to a stressful situation. According to Olson and colleagues (1980), such couples may have difficulty adjusting to the demands of caring for a child with a disability.

When adaptability is very high (very flexible), there is too much agreement within the couple and too little autonomy (Olson, 2000). Very flexible couples are characterized by instability and inconsistent change, they have few rules to live by, and rules that do exist are changed frequently.

According to Olson (1992), communication is a vital aspect of the Circumplex Model because it facilitates movement between cohesion and adaptability. Communication between members of marital systems is critical for functioning and crisis management. Communication is measured by focusing on the couple as a group. A couple's listening and speaking skills, amount of self-disclosure, clarity and continuity, respect and regard, are important components of communication (Seligman & Darling, 1997.) Balanced systems tend to have better communication skills when compared to unbalanced systems (Olson, 1991).

In summary, research regarding the use of the Circumplex Model has concluded that couple relationships with moderate levels of cohesion (separated or connected) tend to balance the two dimensions in a functional manner. High levels of cohesion (very connected) or low levels of cohesion (disengaged) are apt to be problematic for individuals and couples. Couple relationships with moderate levels of adaptability (structured or flexible) tend to balance the two dimensions in a functional manner. High levels of adaptability (very flexible) or low levels of adaptability (rigid) are apt to be problematic for couples (Anderson, 1986; Maynard & Olson, 1987; Olson, 2000; Thomas & Ozechowski, 2000).

From a family systems perspective, cohesion and adaptability can reflect either a successful or problematic system in terms of functioning and crisis management. Whether or not the couple system is successful depends on the interactions among couple members (Klein & White, 1996; Olson, 1991). Thus, according to Broderick (1993), when working with couples with a child with a disability, the emphasis should be on strengthening patterns of couple interaction.

Individual Coping Style

Why do some couples raising a child with a disability cope successfully, while others struggle to maintain equilibrium? One answer lies in their response to the stressors and strains of raising a child with a disability. Responses are exhibited by individual coping styles. Margalit and Ankonina (1991) defined coping style as cognitions and behaviors used to evaluate stressors and strains and initiate activities, with the aim of decreasing their impact.

Seligman and Darling (1997) suggested that individuals and couples raising a child with a disability follow a predictable pattern of coping and coming to terms with the disability. Their first concern involves obtaining an accurate diagnosis, and making emotional adjustments. Second, they clarify personal views, and deal with the reactions of other people. Third, they deal with the issues of adjusting as the child ages. Fourth, they recognize and adapt to their new responsibilities. Fifth, they reestablish their relationship to each other. Couples may follow this pattern individually or collectively.

According to McCubbin and Patterson (1981), coping style can be classified by internal and external strategies. Internal strategies often involve "passive appraisal," the idea that with time problems will resolve themselves; and "reframing," which involves making attitudinal adjustments. External strategies often involve social support from external family members and the community, including spiritual support, and the use of community and professional resources. Couples may experience internal and external coping strategies individually and collectively.

In addition, Margalit and Ankonina (1991) found that coping style appears to fall into two major categories: adaptive and palliative. Adaptive coping strategies are attempts to change the source of the stress, or to adapt to the stress. Additional adaptive strategies include seeking information and social support from others. Adaptive coping styles have been shown to be the most effective in reducing stress. Palliative coping strategies are based on emotion, and include strategies such as avoidance, self-blaming, and wishful thinking. Palliative coping styles may result in short-term stress reduction, but they are less effective in reducing long-term and chronic stress. Couples may experience adaptive and palliative coping styles individually, collectively, or both.

Bailey and Smith (2000) and Bailey and Skinner (1999), in accordance with Bronfenbrenner's (1979) sociology ecology model, indicate that a couples' ability to cope effectively with the stressors and strains associated with raising a child with a disability is influenced by the larger social systems in which they individually and collectively thrive. Essentially, an individual's response to an event and his or her coping methods are derived from a combination of the following: historical context, regional attitudes and norms, ethnic and cultural beliefs, religiosity, values, parent's gender, parent's educational level, socioeconomic status, severity of the child's disability, child's age, couple cohesion and adaptability, level of emotional expressiveness within the couple, informal networking, and social-emotional support.

Effective coping styles can lessen the negative effects of the stressors of raising a child with a disability and are beneficial to individual and couple functioning. Thus, to cope successfully, individuals and couples must learn and implement effective coping strategies, such as thinking about the problem in a different way, looking at alternate solutions, and seeking social supports (Bailey & Smith, 2000). Effective coping strategies can be facilitated by helping couples identify their individual strengths and resources, and providing means for them to build upon these assets (Judge, 1998).

Sources of Family Support

Couples raising a child with a disability need emotional and practical means of support (Kerr & McIntosh, 1999). According to Carpenter (2000), family support, be it nuclear or extended, is the most ideal form of emotional and practical support. Such support has been found to be a great benefit to couples raising a child with a disability (Trivette & Dunst, 1990).

Mirfin-Vetich and associates (1997) examined the role of family support as it pertains to couples raising a child with a disability and found that families fell into two distinct groups: involved and less involved. Involved families were most supportive of each other, whereas, less involved families were less supportive of each other. However, it is important to note that neither the child's type of disability nor the severity of the disability was found to influence the amount of support couples received from other family members. Rather, preexisting family relationship characteristics were identified as the strongest predictor of support. Specifically, the following factors were found to have a significant effect on the probability that couples would receive emotional and practical support from nuclear and extended family:

- Family members displayed immediate unconditional love and acceptance of the child, despite initial sadness.
- Family members reacted positively, and provided support at all times, not just during a crisis.
- Family members viewed association with one another as vital for healthy development and functioning.
- Family members shared a climate of open communication and trust.

- Family members have a positive, close and supportive relationship history.
- Family members recognized the need for support from other family members and the community.

Thus, Mirfin-Vetich and colleagues concluded that love, as well as healthy coping skills, positive family associations, and the ability to identify areas of needed support are essential for healthy couple functioning and family relationships. Accordingly, Trivette and Dunst (1990) stated that the most important determinant for successful family functioning for most couples with a child with a disability is the availability of supportive resources within the family.

Seligman and Darling (1997) found family support was instrumental in aiding normalization, which is the return to more traditional family functioning. In general, a normalized lifestyle for families in the United States includes, but is not limited to: parental employment, suitable educational placement for the child with a disability, access to appropriate health care, housing, healthy social relationships with family and friends, leisure time, freedom of movement in public, and sufficient financial resources. Overall, normalization has been found to be a continuing process that results from internal and external sources of family support working together to aid the child with a disability and their family to reach optimum development.

Greeff (2000) found that whether or not children with disabilities develop optimally or poorly depends a great deal on the amount of family support and the degree to which the parents are able to spend time with the child. Barnett and Boyce (1995) found that parents of children with disabilities and parents of typically developing children allocated their time similarly.

Carpenter (2000) found that parents of children with disabilities, compared to typically developing children, experienced more child-care related stress and indicated a greater need for external family and community support. Scherman and Emmett (1995) concluded that professionals should look more closely at the extended networks of families and the contributions these extended family members provide. Specifically, grandparents have been unrecognized and underutilized as important resources. Their involvement benefits the child with the disability as well as the entire family system (Sandler & Warren, 1995).

Overall, in regard to the effects of emotional and practical means of support on the couple system, family support followed by community support have been shown to greatly benefit couples raising a child with a disability (Bischoff & Tingstrom, 1991; Bjorck-Akesson & Granlund, 1995).

Sources of Community Support

Social and community support can be mediating factors in helping couples to meet the stressful demands of raising a child with a disability. Social and community support consist of people and groups that oftentimes are helpful to parents raising a child with a disability. They include medical professionals, friends and neighbors, early intervention programs, support groups, and government policy. Bjorck-Akesson and Granlund (1995) found that community support has been shown to greatly benefit couples and families. In addition, Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) stated that community support has been shown to reduce couple stress;

specifically, they found that parents with greater community support were more positive in their behavior and attitudes toward their child with a disability than parents without such support.

Kazak and Wilcox (1984) found that having limited material resources, harboring unrealistic expectations, and having few social contacts are detrimental to couple functioning and crisis management. Kazak and Marvin (1984) posit that there are three components of social networks that aid in helping couples that are raising a child with a disability: network size, network density, and boundary density.

Network size is defined as the number of persons providing different types of support such as spiritual, medical, emotional, and instrumental. In general the larger the social network, the greater the possibility of successful coping.

Network density is defined as the degree to which members of an individual's social network know each other, independent of the child with a disability. Density provides an indication of the interconnectedness of the couples' social networks.

Boundary density is defined as the amount of the network membership that is shared by all family members. Boundary density primarily includes the number of network members who both parents know and utilize.

McCubbin and Huang (1989) found that the social networks of couples with a child with a disability were fairly dense, signifying that the individuals from whom help was sought knew and socialized with each other. When fewer social networks were available to couples, the role of community support became more crucial. In addition, they observed that using social support is a major component of coping strategies.

Kazak and Wilcox (1984) stated that there are three areas of community support applicable to understanding the ecological context of couples in relation to social networks. First, is the nature of existing stresses and strains on the couple system, second, isolation from support networks, and third, identifying internal sources of support as well as external sources of support. Hence, it is the availability and type of internal and external sources of social support that help couples to cope with some of the more arduous tasks of raising a child with a disability (Simpson, 1990).

Carpenter (2000) identified both internal and external sources of support as contributing to coping and adaptability. Social support was also found to reduce distress, and encourage positive personal, couple, family, and child functioning, enabling parents to maintain a sense of normalcy (Bjorck-Akesson & Granlund, 1995; Krahn, 1993).

According to Cigno (1999) the most effective types of community support are those that deal with education, facilitation, and provide personal advocacy. In some cases, behavioral parent training is used extensively to train parents to modify diverse behavioral problems, and to teach such adaptive skills as feeding, motor imitation, self-help, appropriate play, and compliance behavior in their children (Ziolko, 1991).

Overall, the greatest sources of community support were parent-to-parent support. Kerr and McIntosh (1999) have suggested that parents of children with disabilities are uniquely qualified to help each other because they are experiencing similar problems. Support groups that are focused on the couple and family systems, as well as sources of community support, benefit couple members the most since they provide interaction with other couples and families (Bjorck-Akesson & Granlund, 1995).

Summary of Literature

It has been well documented that couples raising a child with a disability are faced with many unique stressors and strains that are uncommon for couples raising a typically developing child (Turnbull et al., 1993). However, despite the many obstacles associated with raising a child with a disability, many of these couples develop the resources and capabilities necessary to successfully manage the care of their child with a disability while sustaining their marriage (Seligman, 1999). The impact of childhood disability on the couple system has been identified as an area of research needing more study (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998; Korn, Chess, & Fernandez, 1978; Lyon & Lyon, 1991).

Research focusing on moderator variables of marital satisfaction in couples raising a child with a disability found that cohesion and adaptability in the form of spousal support can play a key role in a couples ability to successfully meet the demands of raising a child with a disability (McKinney & Patterson, 1987). Individual coping style, and sources of family and community support have also been identified as helping mediators (Bailey & Smith, 2000).

McCubbin and Huang (1989) recognize the pressing need for greater understanding and clarification of the characteristics within couples that play a major role in buffering the ongoing stressors and strains associated with raising a child with a disability. In particular, the impact on couples raising a child with cerebral palsy has not been studied nearly as extensively as when the child has Down syndrome, spina bifida, or autism (Joesch, 1997; Murphy, 1982).

Using the theoretical frameworks of Family Systems Theory (Bowen, 1978) and the Social Ecology Model (Bronfenbrenner, 1979), this study examined the relationship between couple cohesion and adaptability, individual coping style, and sources of family and community support, and their influences on the marital satisfaction of couples raising a child between the ages of 3-17 years with a diagnosis of cerebral palsy.

Research Questions and Hypotheses

Data were collected and analyzed based on the following research question: To what extent is the marital satisfaction of couples raising a child between the ages of 3-17 years with a diagnosis of cerebral palsy influenced by couple cohesion and adaptability, individual coping style, and sources of family and community support? Specifically, the following aspects of couple relationships and functioning were examined to answer this question.

1. Does the level of couple cohesion as measured by FACES II affect marital satisfaction in couples raising a child with cerebral palsy?
2. Does the level of couple adaptability as measured by FACES II affect marital satisfaction in couples raising a child with cerebral palsy?
3. How does individual coping style, as measured by the Coping Health Inventory for Parents influence marital satisfaction? Is there a relationship between Coping Style I: Maintaining Family Interaction, Cooperation, and an Optimistic Definition of the Situation, and marital satisfaction, Coping Style II: Maintaining Social Support, Self-Esteem, and Psychological Stability, and marital satisfaction,

and Coping Style III: Understanding the Health Care Situation by Communicating with other Parents and Working with a Health Care Team, and marital satisfaction?

4. Do couples raising a child with cerebral palsy that have a strong family support system as measured by the FSS exhibit higher levels of marital satisfaction than couples with poor familial support?
5. Do couples raising a child with cerebral palsy that have a network of social and professional relationships in the community as measured by the FSS exhibit higher levels of marital satisfaction than couples that do not have external support?
6. Is there a relationship between the severity of the child's disability and the parent's level of marital satisfaction?

It is hypothesized that:

1. Ho: The level of couple cohesion does not affect marital satisfaction in couples raising a child with cerebral palsy.
2. Ho: The level of couple adaptability does not affect marital satisfaction in couples raising a child with cerebral palsy.
3. Ho: Individual coping style does not influence marital satisfaction. There is no relationship between Coping Style I: Maintaining Family Interaction, Cooperation, and an Optimistic Definition of the Situation, and marital satisfaction. There is no relationship between Coping Style II: Maintaining Social Support, Self-Esteem, and Psychological Stability, and marital satisfaction. There

is no relationship between Coping Style III: Understanding the Health Care Situation by Communicating with other Parents and Working with a Health Care Team, and marital satisfaction, as measured by the Coping Health Inventory for Parents.

4. Ho: Couples raising a child with cerebral palsy that have a strong family support system will not exhibit higher levels of marital satisfaction than couples with poor familial support.
5. Ho: Couples raising a child with cerebral palsy that have a network of social and professional relationships in the community will not exhibit higher levels of marital satisfaction than couples that do not have external support.
6. Ho: There is no relationship between the severity of the child's disability and the parent's level of marital satisfaction.

CHAPTER III

RESEARCH METHODOLOGY

Research Design

This study employed a quantitative approach to examine factors that influence marital satisfaction in couples raising a child between the ages of 3-17 years with a diagnosis of cerebral palsy. Specifically, in order to answer the research questions, the following aspects of couple relationships and functioning were examined: couple cohesion and adaptability, individual coping style, sources of family and community support, and marital satisfaction.

Population and Sample Recruitment

The sample for this study consisted of 28 married couples raising their biological or adopted child with a diagnosis of cerebral palsy, who was between the ages of 3-17 years. A sample of 30 was proposed; however, after 7 months of continuous recruitment efforts, committee approval was obtained to analyze data with a sample of 28 couples. Because the effects of cerebral palsy vary from individual to individual, resulting in different physical and intellectual abilities, participants were classified as raising a child who is mildly/moderately or severely impaired by cerebral palsy. This classification was based on parent disclosure. This classification was important because the severity of the disability: mild/moderate, or severe, can have substantial implications for marital satisfaction (McCubbin & Huang, 1989).

Permission was obtained from the USU Institutional Review Board (IRB) to survey human subjects. Permission also was obtained from the various participating organizations (United Cerebral Palsy of Utah, the Utah Parent Center, the Center for Persons with Disabilities at Utah State University, and the Utah Independent Living Center). Refer to Appendix C for the letters of agreement. Informed consent was implied by the respondent's willingness to complete and return the questionnaire.

Participants were informed about this research study by methods based on the individual policies and procedures of each organization, and in compliance with USU IRB policy.

Participants in this study were recruited from service sources in Northern and Central Utah. Specifically, participants were recruited through referrals of professionals working in local organizations that provide services and support for persons with disabilities and their families. United Cerebral Palsy of Utah, the Utah Parent Center, the Center for Persons with Disabilities at Utah State University, and the Utah Independent Living Center referred potential participants to the study. Participant couples also referred other couples that met the criteria for the study.

United Cerebral Palsy of Utah is a leading source of information, as well as, service provider and advocate for the rights of persons with cerebral palsy. United Cerebral Palsy of Utah currently serves approximately 650 families raising a child with cerebral palsy each year (J. Petty, personal communication, November 7, 2002).

United Cerebral Palsy of Utah permitted the student researcher to attend 'Family Ties,' a parent/family support group that meets four times a year. The student researcher had planned to attend the Family Ties activity in June; however, it was canceled. The student researcher did attend the Family Ties activity in September. The student researcher served as a volunteer for the event, and had a booth set up near the welcome table where interested couples could speak with the student researcher and learn more about the study. Ten couples fit the criteria for the study, seven couples agreed to participate, and six couples returned their surveys.

In addition, the student researcher was allowed to place flyers in their facility and run an ad in their newsletter, which is printed every other month. After no responses were generated from the flyers and newsletter, United Cerebral Palsy of Utah mailed the recruitment letter to the families they serve. This mailing of approximately 650 letters resulted in four couples responding, with three couples returning their surveys. One couple was referred to the student researcher by name at the beginning of the study by the center's director.

The Utah Parent Center works with families of children with physical, mental, learning, and emotional disabilities. The Utah Parent Center helps families obtain appropriate education and services for their children with disabilities, works to improve educational services, resolves problems between families and agencies, and connects families to appropriate community resources. The Utah Parent Center currently serves' approximately 51 families raising a child with cerebral palsy each year (K. Post, personal communication, October 1, 2002).

The Utah Parent Center sent the recruitment letter to parents informing them of the study. This first mailing was sent only to families with a child with cerebral palsy, approximately 51 families. After no responses were generated, an email with the recruitment poster attached was sent to these same families. After no response were generated the center director, sent an email to all the families on the centers email mailing list, approximately 200 families. The student researcher also placed flyers in their facility. Unfortunately no responses were generated.

The Center for Persons with Disabilities at Utah State University is a campus organization supporting students and members of the community by providing interdisciplinary community service, continuing education, and research. The Center for Persons with Disabilities at Utah State University currently serves approximately 12 families with a child with cerebral palsy each year (G. Boyce, personal communication, November 8, 2002).

The Center for Persons with Disabilities at Utah State University permitted the student researcher to post flyers in their facility. An ad was also run in their quarterly newsletter. Unfortunately no responses were generated.

The Utah Independent Living Center provides independent living services, to compliment already existing community services. The staff at the Utah Independent Living Center is comprised of individuals with physical and intellectual disabilities. The Utah Independent Living Center currently serves approximately 14 families with a child with cerebral palsy each year (S. Ratner, personal communication, November 7, 2002).

The Utah Independent Living Center permitted the student researcher to post flyers in their facility. Unfortunately no responses were generated.

Each participating organization also agreed to allow the student researcher to leave copies of the questionnaire at their front desks, and to notify the student researcher of any summer camps, and so forth that families would be attending. Arrangements were made for the student researcher to check in once a week. Refer to Appendix B for a sample of the ad, flyer, postcard, and recruitment letter and postcard.

Five participating couples referred another couple, four of which returned surveys. The student researcher followed-up on 87 referrals from a network of her family, friends, and co-workers, resulting in 18 families meeting the criteria and agreeing to participate, with fourteen of those families returning their surveys. In total 28 couples participated.

Sample Demographics

In order to gain an understanding of the home environment and couple dynamics, demographic information was collected regarding participant's age, ethnicity/race, education, occupation, income, religious affiliation, duration of marriage, age and gender of their child with cerebral palsy, as well as the number of siblings in the home. Appendix A contains the measure of demographic information.

The majority (50%) of participants in this study were between 36 to 45 years of age ($M = 40.6$, $SD = 8.4$ for husbands, and $M = 38.2$, $SD = 7.3$ for wives). In addition, the vast majority of participants (95%) self identified as Caucasian. One couple was Native American and the wife in one couple was Hispanic.

The modal level of education among wives in this sample was some college. Among sample husbands, it was a bachelor's degree. In regards to occupation, 28.5% of husbands reported working in a professional position, with 92.8% of husbands working fulltime. Just over 50% of wives reported being homemakers. The annual combined income most frequently reported by the couples was $20,000 to $39,999.

Just over 82% of husbands and 86% of wives indicated affiliation with The Church of Jesus Christ of Latter-day Saints (LDS). The majority of couples were in their first marriage for both partners (78.5% for husbands and 85.7% for wives). The length of marriage most frequently reported by the couples was 11 to 15 years.

The number of children living in the home, including the child with cerebral palsy ranged from 1-7 children with a mean of three (M = 3.3, *SD* = 1.6). Nearly 40% of the children with cerebral palsy in this study were middle children in terms of birth order. It is also interesting to note that one child was a twin, and two other children from separate families were triplets. One couple reported taking care of the wife's 43-year-old sister "who has Down syndrome and is like a child." On average, most of the children with cerebral palsy in this study were eight years old (M = 8.5, *SD* = 4.2). The vast majority of the children with cerebral palsy in this study were male (82.1%).

In regards to classification of cerebral palsy: 16.1% of parents classified their child as mildly impaired, 35.7% as moderately impaired, and 44.6% as severely impaired. (For purposes of statistical analysis, the mild and moderate classifications were combined.) For the majority of parents (60.6%), this classification was based on a doctor's diagnosis. One couple reported not yet receiving an official doctor's diagnosis for their 4-year-old child. The mother wrote, the "doctors don't use the term cerebral palsy. They call it statiz cerebral encephalopathy and leave you guessing. The therapists, et al. call it cerebral palsy." Another mother indicated that her child was also deaf and blind. Table 1 reports husbands' and wives' classification of cerebral palsy based on professional or self-report.

In regards to disability classification, a high percentage of parents (89.3% for husbands and 92.9% for wives) reported that a professional has stated that their child is orthopedically impaired. The majority of parents also reported that they believe that their child is orthopedically impaired (82.1% for husbands and 92.9% for wives).

Couples reported identical perceptions of their child for visual motor problems (82.1%) and communication problems (67.9%). Couples reported that a professional assessment indicated that their child had visual motor problems (78.6% for husbands and 82.1% for wives).

Table 1

Husbands' and Wives' Classification of Cerebral Palsy Based on Professional or Self-Report

	Husband		*Wife*	
Source	*n*	%	*n*	%
Doctors	15	53.5	19	67.8
Tests	5	17.8	5	17.8
Self Report	3	10.7	2	7.1
No Response	5	17.8	2	7.1

Note. $N = 56$.

Nearly 65% of husbands and 67.9% of wives indicated that a professional has stated that their child had communication problems. Parental reports of behavioral problems were 28.6% and 21.4% for husbands and wives respectively; 25% of husbands and 21.4% of wives indicated that a professional has stated that their child has behavioral problems.

Table 2 (p. 45) presents father's perceptions of their child's conditions, and reporting of professional diagnoses. Table 3 (p.46) presents mother's perceptions of their child's conditions, and reporting of professional diagnoses.

Procedures

The recruitment ad, flyer, and letter contained contact information. Interested parents contacted the student researcher by phone, email, or mail. In most instances (86%), the student researcher made the first contact either after receiving a referral, or at the Family Ties activity.

During the initial contact with the couple, the student researcher told the couple about her background and the purpose of the study. Primarily that the information gained from this study might benefit the social sciences and those who work with families with children with disabilities.

Arrangements were then made for the student researcher to either mail or deliver the questionnaire packets to the recruited couples based on their preference and location. Of the surveys returned, 17 were delivered in person by the student researcher and 11 were delivered by mail.

Table 2

Father's Perceptions of Child's Conditions and Reporting of Professional Diagnoses

Condition	*Father's Perceptions* *n*	%	*Professional Diagnoses* *n*	%
Cerebral palsy	27[a]	96.4	27*	96.4
Orthopedically impaired	23	82.1	25	89.3
Visual/motor problems	23	82.1	22	78.6
Communication problems	19	67.9	18	64.3
Visual problems	15	53.6	17	60.7
Seizures (epilepsy, etc.)	14	50.0	16	57.1
Intellectually disabled	13	46.4	14	50.0
Learning disability	13	46.4	12	42.9
Behavioral problems	8	28.6	7	25.0
Attention deficit disorder	5	17.9	4	14.3
Hearing problems	2	7.1	3	10.7
Heart condition	1	3.6	1	3.6

Note. $N = 28$.

[a] One child has not received an official diagnosis of cerebral palsy.

Questionnaire packets included two copies of the self-report questionnaire and two copies of the demographic information, four number 10 business size envelopes, and one 9" x 12" pre-addressed and pre-stamped catalog envelope. One copy of the

Table 3

Mother's Perceptions of Child's Conditions and Reporting of Professional Diagnoses

	Mother's Perceptions		*Professional Diagnoses*	
Condition	*n*	%	*n*	%
Cerebral palsy	27[a]	96.4	27*	96.4
Orthopedically impaired	26	92.9	26	92.9
Visual/motor problems	23	82.1	23	82.1
Communication problems	19	67.9	19	67.9
Visual problems	16	57.1	18	64.3
Intellectually disabled	14	50.0	16	57.1
Learning disability	14	50.0	14	50.0
Seizures (epilepsy, etc.)	12	42.9	13	46.4
Behavioral problems	6	21.4	6	21.4
Attention deficit disorder	4	14.3	4	14.3
Hearing problems	2	7.1	3	10.7
Heart condition	2	7.1	2	7.1

Note. $N = 28$.

[a] One child has not received an official diagnosis of cerebral palsy.

questionnaire was for the husband/father, and the second copy of the questionnaire was for the wife/mother. One copy of the demographic information was for the husband/father, the second copy of the demographic information was for the wife/mother. One business size envelope was for the husband/father questionnaire, the second business size envelope was for the wife/mother questionnaire. The third business size envelope was for the husband/father demographic information, and the fourth business size envelope was for the wife/mother demographic information. Questionnaire packets also included the recruiting postcard in the event that the couple was aware of another couple that might be willing to participate.

Due to the sensitive nature of the data collected, participants were asked only for necessary information and were instructed not to include their name or any other information that would compromise confidentiality. In addition, couples were asked to complete the questionnaire and demographic information individually and in private, and seal them in the respective business size envelopes, which were then placed in the catalog envelope and returned to the student researcher.

It took approximately thirty to forty minutes to complete the questionnaire. The full questionnaire appears in Appendix A.

Previous arrangements were made for the student researcher either to pick up the questionnaire packets or have the couple return them by mail, based on their preference and location. Of the surveys returned, 26 couples preferred to mail them and 2 preferred the student researcher to pick them up. The original time frame for completing the packets was 48-72 hours. However, all couples felt that they needed more time so individual time frames were set for each couple. Most questionnaires were returned within three weeks. If questionnaire packets were not returned within one month, the student researcher placed a friendly reminder phone call or email.

Thirty-six surveys were sent out, with 29 being returned. One survey was not included in the final data analysis because the couple's child with cerebral palsy had passed away two months prior to his parents completing the study questionnaire. The rate of response was 81%. Of the surveys that were not returned, one may have been lost in the mail. When the student researcher followed up with the mother, she was quite perplexed, as the student researcher had received her friend's survey back but not hers; they had been running errands together and mailed them at the same time. The student researcher sent her a gift certificate, since she and her husband had completed the survey and told her she would check with the post office. The remaining couples all promised "to return them soon," but did not respond to the student researcher's follow-up inquiries.

All couples that returned their questionnaire packet received a 10 dollar gift certificate valid at WalMart and Sam's Club, and a hand written thank you note from the student researcher bearing the following statement:

> "Dear, Mr. and Mrs.________________,
>
> Thank you so much for participating in this study. Your contribution is greatly appreciated. Please enjoy this gift certificate as my thanks to you.
>
> Sincerely,
>
> Sarah

The questionnaire packet included a code number linking the participants to the study for the purpose of tracking returned surveys and sending out the gift certificates. The code number was written in black ink on the bottom right side of the catalogue envelope. This link will be destroyed after one year. Only the principal investigator and the student researcher have access to this information, and it is kept in a locked filing cabinet in a locked room.

Measures

Marital Satisfaction Measures

The first measure chosen to assess marital satisfaction in this study was the Revised Dyadic Adjustment Scale (RDAS) (Busby, Christensen, Crane, & Larson, 1995). The RDAS is a 14-item self-report measure using a 6-point Likert scale to gauge the frequency of couple's agreement or disagreement on matters of marital fulfillment. Examples of items include "do you and your spouse engage in outside interest together," and "how often do you and your partner quarrel?"

The RDAS is a reliable, valid, and concise measure based on seven first-order dimensions (decision making, values, affection, stability, conflict, activities, and discussion), and three second-order dimensions (dyadic consensus, dyadic satisfaction, and dyadic cohesion).

The RDAS has repeatedly shown very high internal consistency and reliability in studies. The RDAS had a Cronbach's alpha coefficient of .90 and a SpearmanBrown split half reliability coefficient of $r = .95$. In addition, each subscale demonstrated high reliability with a Cronbach's alpha coefficient of .81 and a SpearmanBrown split half reliability coefficient of $r = .89$ for dyadic consensus; Cronbach's alpha coefficient of .85 and a SpearmanBrown split half reliability coefficient of $r = .88$ for dyadic satisfaction;

and Cronbach's alpha coefficient of .80 and a SpearmanBrown split half reliability coefficient of $r = .80$ for dyadic cohesion (Busby et al., 1995).

Test-retest reliability was not calculated for the RDAS. However, construct validity has been established between the RDAS and its predecessor the Dyadic Adjustment Scale (DAS), ($r = .97, p < .01$) (Busby et al., 1995).

The RDAS is a strong indicator of distressed and non-distressed marriages, and is best used for couples experiencing stress in their relationship. It is administered individually and takes approximately 5 minutes to complete. Table 4 (p. 51) presents the reliability estimates for the RDAS.

The second measure chosen to assess marital satisfaction in this study was The Kansas Marital Satisfaction Scale (KMS) (Schumm et al., 1985). The KMS is a 3-item self-report measure using a 7-point Likert scale to assess satisfaction with spouse, satisfaction with the marriage, and satisfaction with the marital relationship. The survey items include "how satisfied are you with your marriage," "how satisfied are you with your husband (wife) as a spouse," and "how satisfied are you with your relationship with your husband (wife)?"

The KMS has been well researched and documented, and has generally shown very high internal consistency reliability, test-retest reliability, construct validity, and criterion related validity (Schumm et al., 1986). The KMS had a Cronbach's alpha coefficient of .93 and a Spearman rank-order correlation of $r = .67$. The item means for the KMS were 6.21 (*SD* = .84) for satisfaction with spouse, 6.11 (*SD* = .84) for

Table 4

Subscale Reliability Estimates of the RDAS

Subscale	Cronbach's Alpha	Guttman Split-Half	SpearmanBrown Split-Half
Dyadic consensus	.81	.88	.89
Dyadic satisfaction	.85	.88	.88
Dyadic cohesion	.80	.79	.80

satisfaction with marriage, and 5.95 (*SD* = 1.04) for satisfaction with relationship with spouse. Test-retest correlations of .71 were reported over a 10-week period with a range of .62 to .72 over a 6-month period (Schumm et al., 1985).

The KMS correlates substantially with the Revised Dyadic Adjustment Scale (RDAS; Busby et al., 1995). Pearson coefficient for the RDAS and KMS when used together were .78 (Crane & Middleton, 2000).

The KMS is effective in distinguishing between distressed and non-distressed marriages, and is best used for couples experiencing stress in their relationship (Schumm et al., 1985). It is administered individually and takes approximately 1 minute to complete.

Couple Cohesion and Adaptability Measure

The Family Adaptability and Cohesion Evaluation Scales II: Couples Version (FACES II; Olson et al., 1989) was used to assess cohesion and adaptability in the couple relationship. Specifically, it measured the couples' ability to work together to solve most of the problems associated with raising a child with cerebral palsy that confront them over the life course of their child. FACES II is based on the two major dimensions of the Circumplex Model, which are cohesion and adaptability, which was described in chapter two.

FACES II is a 30-item self-report measure using a 5-point Likert scale to measure couple cohesion (emotional bonding between the couple and the individual autonomy of each member of the dyad) and couple adaptability (the ability of the couple to change its power structure, role relationships, and rules in response to developmental and situational stress) (Olson et al., 1989). Examples of items include "we are supportive of each other during times of stress," and "we try new ways of dealing with problems."

Empirical data imply that FACES II does not capture the extremely high categories of "enmeshed" and "chaotic" couples (Olson, 1992). Accordingly, the linear method of scoring and interpretation was used for this study. The cutoff point for the four levels of cohesion and adaptability remain the same, except that categories of enmeshed and chaotic are no longer measured. Instead high scores on the adaptability and cohesion dimensions are reinterpreted as "very connected" and "very flexible," which are more appropriate concepts for scores in that range.

FACES II has repeatedly shown very high internal consistency and reliability. The average correlation among the 30 items has a Cronbach's alpha coefficient of .90. The first dimension, couple cohesion, has a Cronbach's alpha coefficient of .87. The second dimension couple adaptability has a Cronbach's alpha coefficient of .78 (Olson et al., 1989).

The second pattern, Maintaining Social Support, Self-Esteem, and Psychological Stability, is concerned with behaviors that involve the parent's efforts to develop relationships outside of the family unit and engage in activities that enhance feelings of individual identity and self-esteem. In addition, it examines strategies used to manage psychological pressure and tension ($\forall = .79$).

The third pattern, Understanding the Health Care Situation by Communicating with other Parents and Working with a Health Care Team, also includes the parents' relationship with health care workers and other parents of children with a disability. In addition, it looks at ways to increase parent's knowledge and understanding of their child's disability ($\forall = .71$). Factor analysis of the three coping patterns accounted for 71.1% of the variance between the subscales (McCubbin et al., 1981).

Internal validity for the CHIP was determined by conducting a discriminant analysis between low conflict and high conflict families who were raising a child with cerebral palsy. For mothers, coping patterns I and III were positively associated with family cohesiveness ($r = .21, p < .01$; $r = .19, p < .05$) and coping pattern II was positively associated with family expressiveness ($r = .09, p < .05$). For fathers, coping pattern I was positively associated with family cohesiveness ($r = .36, p < .01$). Coping pattern II was positively associated with family organization ($r = .32, p < .01$), and coping pattern III was positively associated with family control ($r = .19, p < .05$) (McCubbin et al., 1981).

Test-retest reliability for the total scale score (sum of the 30 items) was $r = .90$. For the first dimension, couple cohesion, $r = .80$ was reported, and for the second dimension, couple adaptability, $r = .83$. The correlation between the scales is $r = .25$ for cohesion and $r = .65$ for adaptability (Olson et al., 1989).

FACES II is appropriate for parents of children of all ages with or with out a disability. FACES II is administered individually and takes approximately 10 minutes to complete.

Individual Coping Style Measure

The Coping Health Inventory for Parents (CHIP; McCubbin, McCubbin, Nevin & Cauble, 1981) was used as the measure of individual coping style. CHIP is a 45-item self-report measure using a 4-point Likert scale to measure how helpful specific behaviors are to the unique family situation of raising a child with a disability, and parents' perceptions of their response to managing family life. Examples of items include "talking over personal feelings and concerns with spouse," and "allowing myself to get angry."

CHIP is base on three coping patterns: I. Maintaining Family Interaction, Cooperation, and an Optimistic Definition of the Situation; II. Maintaining Social Support, Self-Esteem, and Psychological Stability; and III. Understanding the Health Care Situation by Communicating with other Parents and Working with a Health Care Team. The first pattern Maintaining Family Interaction, Cooperation, and an Optimistic Definition of the Situation is concerned with behaviors that focus on family life, relationships between family members, and the parents' outlook on life when raising a child with a disability ($\forall = .79$).

CHIP is appropriate for parents of children of all ages. It is intended primarily for use with parents of a child with a disability. CHIP is administered individually and takes approximately 15 minutes to complete.

Family and Community Support Measure

The Family Support Scale (FSS) (Dunst et al., 1984) was used to assess the helpfulness of sources of support for families rearing a child with cerebral palsy. The FSS is an 18-item self-report measure using a 6-point Likert scale to gauge the effects of social support on parents' health and well-being, family integrity, parental perceptions of child functioning, and styles of parent-child interaction. Examples of items include "my spouse's parents," and "early childhood intervention programs."

The FSS is based on the Ecological Model developed by Bronfenbrenner (1979) described in chapter two. The FSS includes the following subscales: I: the informal kinship scale (spouse's friends, own friends, other parents, own children, church); II: the social organization items (social groups/clubs, parent group, co-workers); III: the formal kinship scale items (relatives, own parents, spouse or partner's relatives); IV: the immediate family items (spouse, spouse's parents); V: the specialized professional services items (early intervention program, professional helpers, school/daycare); and VI: the generic professional services items (agencies, family/child physician).

The FSS has repeatedly shown high internal consistency and reliability (Dunst et al., 1984). The FSS has a Cronbach's alpha coefficient of .77 and a SpearmanBrown split half reliability coefficient of $r = .75$. The size of both the alpha coefficient and the split-half reliability coefficient indicate that the FSS has substantial internal consistency, and that there is sufficient evidence to substantiate that the scale is measuring sources of support.

Test-retest reliability for the average correlation among the 18-items was $r = .75$ ($SD = .17, p < .001$) and $r = .91$ ($p < .001$) for the total scale score (sum of the 18 items). Only one item (social groups/clubs) had a test-retest correlation of ($r = .26$) that was not statistically significant. All the other reliability coefficients were significant beyond the .005 level (one-tailed test). Factor analysis utilizing varimax rotation accounted for 62% of the variance. The test-retest findings show that family and community support are relatively stable constructs (Dunst et al., 1984).

The criterion validity of the FSS has been established in regards to the relationship between the total scale score, subscale scores, and family, parent, and parent-child outcomes. The total scale score was consistently related to parent and child outcomes, and opportunities to engage in parent-child play (average $r = .40, p < .001$), personal and family well being ($r = .28, p < .01$), and integrity of the family unit ($r = .19$, $p < .05$) (Dunst et al., 1984).

The FSS is a strong indicator of sources of family and community support for families raising a child with a disability. The FSS is appropriate for parents of children of all ages with mental and physical disabilities, as well as at-risk children. It is administered individually and takes approximately 5 minutes to complete. Reliability coefficients for all measures that were used in this study are reported in chapter 4.

Data Analysis

SPSS 10.0 for Windows statistical software was used for the management of data, and data analysis. Questionnaire data obtained from husbands and wives were analyzed using correlation and two-tailed *t* tests. Data analysis was based on the following research question: To what extent is the marital satisfaction of couples raising a child between the ages of 3-17 years with a diagnosis of cerebral palsy influenced by couple cohesion and adaptability, individual coping style, and sources of family and community support?

Due to the fact that there was no theoretical reason to believe that either husbands or wives outcomes would be significantly greater than or less than the population value, or whether or not one population value would be significantly greater or less than the value of another population, two-tailed *t* tests originally were proposed to test hypotheses one, two, and six. However, due to a low sample size, two-tailed *t* tests were used only to test hypothesis six. Instead, correlation analysis was used to test hypotheses one and two, in addition to hypotheses three, four, and five.

Multiple regression was proposed to estimate the combined effects of couple cohesion and adaptability, individual coping style, and sources of family and community support on the marital satisfaction of husbands and of wives. In addition, multiple regression also was proposed to assess the unique effect of couple cohesion and adaptability, individual coping style, and sources of family and community support on the marital satisfaction of husbands and of wives given the presence of the other variables in the model. However, due to the small sample size and relatively high rates of non-utilization of many items of the CHIP and FSS it was not possible to run multiple regression for this study.

Summary

This quantitative study examined marital satisfaction in couples raising a child with cerebral palsy. Twenty-eight married couples, raising their biological or adopted child with a diagnosis of cerebral palsy between the ages of 3-17 years provided information for this study by individually completing a self-report questionnaire. The questionnaire was comprised of measures of couple cohesion and adaptability, individual coping style, sources of family and community support, and marital satisfaction.

Participants were classified as raising a child who is mildly/moderately or severely impaired by cerebral palsy. Participants in this study were recruited from the following service providers in Northern and Central Utah: United Cerebral Palsy of Utah, the Utah Parent Center, the Center for Persons with Disabilities at Utah State University, the Utah Independent Living Center. Additional referrals came from participating couples, and the student researcher's network of family, friends, and coworkers.

Questionnaire packets were delivered or mailed to the participants by the student researcher. All participating couples received a 10 dollar gift certificate to WalMart/Sam's Club.

The Revised Dyadic Adjustment Scale (RDAS; Busby et al., 1995) and the Kansas Marital Satisfaction Scale (KMS; Schumm et al., 1985) were used to assess marital satisfaction. The Family Adaptability and Cohesion Evaluation Scales II: Couples

Version (FACES II; Olson et al., 1989) was used to assess cohesion and adaptability in the couple relationship. The Coping Health Inventory for Parents (CHIP; McCubbin et al., 1981) was used as the measure of individual coping style. The Family Support Scale (FSS; Dunst et al., 1984) was used to assess the helpfulness of sources of support for families rearing a child with cerebral palsy.

SPSS 10.0 for Windows statistical software was used for the management of data, and data analysis. Questionnaire data obtained from husbands and wives was analyzed using correlation, and two-tailed *t* tests.

CHAPTER IV

RESULTS

Questionnaire data obtained from husbands and wives were analyzed using correlation, and two-tailed *t* tests. Data analysis was based on the following research question: To what extent is the marital satisfaction of couples raising a child between the ages of 3-17 years with a diagnosis of cerebral palsy influenced by couple cohesion and adaptability, individual coping style, and sources of family and community support?

Psychometric Properties of the Measure Variables

Testing of internal reliability estimates the tendency and consistency of respondent's answers across individual items within each measure. This analysis is important for assessing how each question adds to or detracts from the reliability within each of the given measures (Walsh & Ollenburger, 2001). Higher alpha coefficients indicate higher consistencies, and tend to assume a more reliable and stable measure. Table 5 presents the internal consistency estimates for each measure used in this study.

Revised Dyadic Adjustment Scale

The RDAS (Busby et al., 1995) was used to gauge the frequency of a couple's agreement or disagreement on matters of marital fulfillment. The RDAS has repeatedly shown very high internal consistency and reliability, as well as construct and predictive validity. In the norming sample, the RDAS has a total Cronbach's alpha coefficient of .90 and a SpearmanBrown split-half reliability coefficient of $r = .95$.

Table 5

Internal Reliability Estimates for Measure Variables

Measure	Husband ∀	Wife ∀	Total ∀
Revised Dyadic Adjustment Scale	.89	.90	.94
Kansas Marital Satisfaction Scale	.96	.98	.94
Family Adaptability and Cohesion Evaluation Scales II: Couples Version	.94	.96	.90
Coping Health Inventory for Parents	.90	.80	.78
Family Support Scale	.65	.72	.56

In the present study, the RDAS had a total Cronbach's alpha coefficient of .94 and a SpearmanBrown split-half reliability coefficient of $r = .94$. For husbands, the RDAS had a Cronbach's alpha coefficient of .89 and a SpearmanBrown split-half reliability coefficient of $r = .85$. For wives, the RDAS had a Cronbach's alpha coefficient of .90 and a SpearmanBrown split-half reliability coefficient of $r = .74$.

In addition, each subscale demonstrated high reliability. For husbands, subscale one, dyadic consensus, had a Cronbach's alpha coefficient of .74 and a SpearmanBrown split-half reliability coefficient of $r = .80$. For wives, subscale one, dyadic consensus, had a Cronbach's alpha coefficient of .88 and a SpearmanBrown split-half reliability coefficient of $r = .92$.

For husbands, subscale two, dyadic satisfaction, had a Cronbach's alpha coefficient of .89 and a SpearmanBrown split-half reliability coefficient of $r = .88$. For wives, subscale two, dyadic satisfaction, had a Cronbach's alpha coefficient of .92 and a SpearmanBrown split-half reliability coefficient of $r = .95$.

For husbands, subscale three, dyadic cohesion, had a Cronbach's alpha coefficient of .81 and a SpearmanBrown split-half reliability coefficient of $r = .82$. For wives, subscale three, dyadic cohesion, had a Cronbach's alpha coefficient of .76 and a SpearmanBrown split-half reliability coefficient of $r = .82$. These reliability measures suggest a high consistency and reliability in the participant's responses across the 28 items.

The RDAS classified 26 husbands (92.9%) and 25 wives (86%) as having non-distressed marriages, and 2 husbands (7.1%) and 3 wives (14%) as having distressed marriages. Classification was based on scores from the husband, the wife, or both being below 48, with a possible range of 14-83, which is consistent with the developer's criteria. National mean scores on the total RDAS are reported as M = 48.0, *SD* = 9.0 (Busby et al., 1995). For this study, mean scores for husbands and wives were: M = 60.4, *SD* = 8.4 for husbands, and M = 62.2, SD = 9.7 for wives.

Kansas Marital Satisfaction Scale

Similarily, the KMS (Schumm et al., 1985) was used to assess satisfaction with spouse, satisfaction with the marriage, and satisfaction with the marital relationship. The KMS has generally shown very high internal consistency reliability, test-retest reliability, construct validity, and criterion related validity. In the norming sample, the KMS had a total Cronbach's alpha coefficient of .93. A Cronbach's alpha coefficient of .94 for husbands and a Cronbach's alpha coefficient of .92 for wives.

In the present study, the KMS had a total Cronbach's alpha coefficient of .94 and a SpearmanBrown split-half reliability of $r = .79$. For husbands, the KMS had a Cronbach's alpha coefficient of .96 and SpearmanBrown split-half reliability of $r = .96$. For wives, the KMS had a Cronbach's alpha coefficient of .98 and a SpearmanBrown split-half reliability of $r = .97$.

The item means for the total KMS were M = 5.47 (*SD* = 1.48). The range of possible scores for the KMS is 3-21. For satisfaction with spouse, M = 5.48 (*SD* = 1.46), for satisfaction with marriage, M = 5.61 (*SD* = 1.52), and M = 5.32 (*SD* = 1.47) for satisfaction with relationship with spouse.

For husbands, the item means for the KMS were M = 5.50 (*SD* = 1.35) for satisfaction with spouse, M = 5.68 (*SD* = 1.34) for satisfaction with marriage, and M = 5.36 (*SD* = 1.34) for satisfaction with relationship with spouse. For wives, the item means for the KMS were M = 5.46 (*SD* = 1.57) for satisfaction with spouse, M = 5.54 (*SD* = 1.69) for satisfaction with marriage, and M = 5.29 (*SD* = 1.61) for satisfaction with relationship with spouse. These findings suggest a high consistency and reliability in the participant's responses across the 6 items.

The KMS classified 25 husbands (86%) and 25 wives (86%) as having non-distressed marriages, and 3 husbands (14%) and 3 wives (14%) as having distressed marriages. Classification was based on scores from the husband, the wife, or both being below 17, which is consistent with the developer's criteria (M = 16.5, *SD* = 3.9 for husbands and M = 16.3, *SD* = 4.8 for wives).

For this study, the correlation between the total RDAS and the total KMS was significant ($r = .82, p < .01$). Table 6 contains husband's correlations with wives on the RDAS and KMS.

Family Adaptability and Cohesion Evaluation Scales II: Couples Version

FACES II: Couples Version (Olson et al., 1989) was used to assess cohesion and adaptability in the couple relationship. FACES has repeatedly shown very high internal consistency and reliability. In the present study, FACES II: Couples Version has a Cronbach's alpha coefficient of .90 and a SpearmanBrown split-half reliability coefficient of $r = .92$. For husbands, FACES II: Couples Version has a Cronbach's alpha coefficient of .94 and a SpearmanBrown split-half reliability coefficient of $r = .50$.

Table 6

Relationship Between Husband RDAS and KMS and Wife RDAS and KMS

	Husband RDAS	Wife RDAS	Husband KMS	Wife KMS
Husband RDAS	- -	.84	.72	.63
Wife RDAS	.84	- -	.74	.76
Husband KMS	.72	.74	- -	.65
Wife KMS	.63	.76	.65	- -

Note. All coefficients are significant at $p < .05$.

For wives, FACES II: Couples Version has a Cronbach's alpha coefficient of .96 and a SpearmanBrown split-half reliability coefficient of $r = .78$. This suggests a high consistency and reliability in the participant's responses across the 60 items. Table 7 presents the level of cohesion for husbands and wives in this study. Various levels of cohesion were described in chapter 2 (p. 21). Table 8 presents the level of adaptability for husbands and wives in this study. Various levels of adaptability were described in chapter 2 (p. 23).

Table 7

Circumplex Model: Level of Cohesion for Husbands and Wives (N = 56)

	Husband		Wife	
Characteristics	*n*	%	*n*	%
Disengaged – low	1	3.6	2	7.1
Disengaged – high	2	7.1	3	10.7
Separated – low	3	10.7	3	10.7
Separated – high	1	3.6	2	7.1
Connected – low	6	21.4	5	17.9
Connected – high	8	28.6	5	17.9
Very connected – low	4	14.3	4	14.3
Very connected – high	3	10.7	4	14.3

Table 8

Circumplex Model: Level of Adaptability for Husbands and Wives (N = 56)

	Husband		Wife	
Characteristics	*n*	%	*n*	%
Very flexible – high	0	0.0	0	0.0
Very flexible – low	9	32.1	9	32.1
Flexible – high	5	17.9	5	17.9
Flexible – low	2	7.1	2	7.1
Structured – high	3	10.7	6	21.4
Structured – low	6	21.4	2	7.1
Rigid – high	3	10.7	3	10.7
Rigid – low	0	0.0	1	3.6

Coping Health Inventory for Parents

CHIP (McCubbin et al., 1981) was used to measure the helpfulness of specific coping behaviors and to assess parents' perceptions of their response to managing family life. CHIP has repeatedly shown very high reliability and internal validity.

In the present study, CHIP has a total Cronbach's alpha coefficient of .78. CHIP has a Cronbach's alpha coefficient of .90 and .80, respectively, for husbands and wives.

The first coping pattern, Maintaining Family Interaction, Cooperation, and an Optimistic Definition of the Situation, has Cronbach's alpha coefficients of .81 and .76 for husbands and wives, respectively. The second pattern, Maintaining Social Support, Self-Esteem, and Psychological Stability, has Cronbach's alpha coefficients of .84 and .72 for husbands and wives respectively. The third pattern, Understanding the Health Care Situation by Communicating with other Parents and Working with a Health Care Team, has Cronbach's alpha coefficients of .72 and .67 for husbands and wives respectively.

In order to effectively answer research question III, CHIP was calculated by looking at the relationships between marital satisfaction and the three CHIP coping styles. Possible scores for Coping Style I: Maintaining Family Interaction, Cooperation, and an Optimistic Definition of the Situation range from 19-76; for Coping Style II: Maintaining Social Support, Self-Esteem, and Psychological Stability possible scores range from 19-72; and for Coping Style III: Understanding the Health Care Situation by Communicating with other Parents and Working with a Health Care Team possible scores range from 19-32. Respondents were given the option of selecting "chose not to use" or "not possible." These responses were coded as 0. Table 9 (p. 68) presents the rates of endorsement of "chose not to use" and "not possible" for selected items in the CHIP by husband and wife.

Family Support Scale

FSS (Dunst et al., 1984) was used to assess the helpfulness of sources of family and community support for families rearing a child with cerebral palsy. For this study, the subscales for sources of family support and sources of community support did not hold together collectively for either husbands or wives. This may be due in part to the small sample size. In addition, respondents were given the option of selecting "not available"

Table 9

Highest Rates of Endorsement of "Chose Not to Use" and "Not Possible" for the CHIP by Husband and Wife (N = 56)

Coping Style	Husband *n*	Wife *n*
I: Maintaining Family Interaction, Cooperation, and an Optimistic Definition of the Situation		
Believing that my child(ren) will get better	15	11
Taking good care of all the medical equipment at home	9	6
II: Maintaining Social Support, Self-Esteem, and Psychological Stability		
Entertaining friends in our home	10	9
Talking to someone (not professional counselor/doctor) about how I feel	11	5
III: Understanding the Health Care Situation by Communicating with Other Parents and Working with a Health Care Team		
Reading about how other persons in my situation handle things	11	4
Reading more about cerebral palsy	9	4

when describing the helpfulness of various sources of support; such responses were coded as 0. Table 10 (p. 69) shows the internal reliability estimates for the six subscales of the FSS for husbands and wives.

The size of the alpha coefficients for husbands and wives for dimensions of both family and community support indicates that the FSS has weak reliability; thus, there is not sufficient evidence to substantiate that the scale is measuring sources of family and community support. Table 11 (p. 70) presents the mean and standard deviation scores for each subscale of the FSS. For each item in the scale, possible scores range from 1-5.

Proposed Data Analysis

Due to the fact that there was no theoretical reason to believe that either husbands or wives' outcomes would be significantly greater than or less than the population value, or whether or not one population value would be significantly greater or less than the value of another population, two-tailed *t* tests were originally proposed to test hypotheses one, two, and six.

Table 10

Internal Reliability Estimates for FSS Subscales for Husbands and Wives

Subscale	Husband ∀	Wife ∀
Family support		
Informal (friends, church)	.54	.30
Formal (parents, relatives)	.61	.58
Nuclear family	.24	.03
Community support		
Social organizations	.48	.76
Specialized professional services	-.01	.50
Generic professional services	.24	.49

Table 11

Mean and Standard Deviation Scores for FSS Subscales

	Husband			Wife		
Items	*M*	*SD*	*n*	*M*	*SD*	*n*
Sources of family support informal kinship:						
Spouse's friends	2.37	0.92	27	1.61	1.19	18
Friends	2.07	0.99	27	2.36	1.15	25
Other parents	2.16	0.85	18	2.15	1.26	20
Own children	3.80	1.09	26	3.69	1.40	26
Church	2.69	1.32	23	2.41	1.10	24
Formal kinship:						
relatives/kin	2.27	1.20	22	2.34	1.11	23
parents	2.78	1.18	19	2.90	1.41	22
Spouse's relatives/kin	2.59	1.18	22	2.47	1.47	23
Nuclear family:						
husband/wife	4.96	0.18	28	4.35	0.98	28
Spouse's parents	2.76	1.37	21	2.35	1.26	20
Sources of community support social organizations:						
Social groups/clubs	1.94	1.25	18	2.14	1.23	14
Parent groups	1.68	0.89	22	2.23	1.16	13
Co-workers	1.59	0.85	22	1.40	1.05	15

(*Table 11 continues*)

Items	Husband			Wife .		
	M	*SD*	*n*	*M*	*SD*	*n*
Specialized professional services:						
Early intervention program	3.05	1.51	17	3.77	1.21	18
Professional helpers	3.85	0.93	28	3.92	1.05	28
School/day care	3.81	0.87	27	3.72	1.20	25
Generic professional services:						
Professional agencies	2.65	1.26	20	2.64	1.21	14
Family/child's physician	3.29	1.10	27	3.33	1.14	27

However, due to a low sample size, two-tailed *t* tests were used only to test hypothesis six. Instead, correlation analysis was used to test hypotheses one, two, and three.

Multiple regression was proposed to estimate the combined effects of couple cohesion and adaptability, individual coping style, and sources of family and community support on the marital satisfaction of husbands and of wives. In addition, multiple regression also was proposed to assess the unique effect of couple cohesion and adaptability, individual coping style, and sources of family and community support on the marital satisfaction of husbands and of wives given the presence of the other variables in the model. However, due to the low sample size and relatively high rates of non-utilization of many items of the CHIP and FSS it was not possible to run multiple regression for this study.

Research Questions

Research Question I

It was hypothesized that the level of couple cohesion does not affect marital satisfaction in couples raising a child with cerebral palsy. Husband and wife samples differed only slightly from one another on most cohesion variables (range 1-5) in terms of describing their feelings regarding their relationship with their spouse. Bivariate correlations between the cohesion variables in FACES II and marital satisfaction included in this sample may be found in Table 12. All bivariate correlations were statistically significant for both husbands and wives.

For this study, cohesion was found to be significantly and positively correlated with marital satisfaction for both husbands and wives, thus we reject the null hypothesis that the level of couple cohesion does not relate to marital satisfaction in couples raising a child with cerebral palsy.

Table 12

Relationship Between Husband Cohesion and Wife Cohesion and Marital Satisfaction as Measured by RDAS and KMS

	Husband Cohesion	Wife Cohesion
RDAS	.81	.85
KMS	.74	.85

Note. All coefficients are significant at $p < .05$.

Research Question II

It was hypothesized that the level of couple adaptability does not affect marital satisfaction in couples raising a child with cerebral palsy. Husband and wife samples differed only slightly from one another on most adaptability variables (range 1-5) in terms of describing their feelings regarding their relationship with their spouse. Bivariate correlations between the adaptability variables in FACES II and marital satisfaction included in this sample may be found in Table 13. All bivariate correlations were statistically significant for both husbands and wives.

For this study, couple adaptability was found to be significantly and positively correlated with marital satisfaction for both husbands and wives, thus we reject the null hypothesis that the level of couple adaptability does not affect marital satisfaction in couples raising a child with cerebral palsy.

Research Question III

It was hypothesized that individual coping style does not influence marital satisfaction in couples raising a child with cerebral palsy. Specifically, it was

Table 13

Relationship Between Husband Adaptability and Wife Adaptability and Marital Satisfaction as Measured by RDAS and KMS

	Husband Adaptability	Wife Adaptability
RDAS	.77	.83
KMS	.60	.69

Note. All coefficients are significant at $p < .05$.

hypothesized that there is no relationship between Coping Style I: Maintaining Family Interaction, Cooperation, and an Optimistic Definition of the Situation, and marital satisfaction. There is no relationship between Coping Style II: Maintaining Social Support, Self-Esteem, and Psychological Stability, and marital satisfaction. There is no relationship between Coping Style III: Understanding the Health Care Situation by Communicating with other Parents and Working with a Health Care Team, and marital satisfaction.

As indicated in the following tables, the husband and wife samples differed slightly from one another on most of the CHIP variables in terms of describing coping behaviors that have been effective for them in terms of raising their child with cerebral palsy. Husbands reported higher levels of family integration, and maintaining social support. Wives reported higher levels of understanding the health care situation. Table 14 (p. 75) reports the total CHIP mean scores for husbands and wives, and Table 15 (p.75) reports the coping style mean scores for husbands and wives. Possible scores for the total CHIP range from 45-180. For subscale I possible scores range from 19-76, for subscale II possible scores range from 18-72 and for subscale III possible scores range from 8-32.

In this study, husband's coping style was not found to be significantly and positively correlated with their level of marital satisfaction, thus we cannot reject the null hypothesis that for husbands there is no relationship between Coping Style I: Family integration, cooperation, and an optimistic definition of the situation, and marital satisfaction. There is no relationship between Coping Style II: Maintaining

Table 14

Total CHIP Mean Scores and Standard Deviations for Husbands and Wives (N = 56)

	M	*SD*
Husband	53.96	8.36
Wife	58.14	8.60

Table 15

CHIP Coping Style Means and Standard Deviations for Husbands and Wives (N = 56)

Coping Style	Husband		Wife	
	M	*SD*	*M*	*SD*
I: Maintaining family interaction, cooperation, and an optimistic definition of the situation	38.93	8.41	43.00	7.52
II: Maintaining social support, self-esteem, and psychological stability	24.43	10.54	29.75	8.54
III: Understanding the health care situation by communicating with other parents and working with a health care team	11.32	4.49	15.29	4.49

social support, self-esteem, and psychological stability, and marital satisfaction. There is no relationship between Coping Style III: Understanding the health care situation by communicating with other parents and working with a health care team, and marital satisfaction.

For wives Coping Style I: Family integration, cooperation, and an optimistic definition of the situation, and marital satisfaction, was found to be positively associated with their marital satisfaction, ($r = .55, p \leq .002$). Thus we reject the null hypothesis that for wives there is no relationship between Coping Style I: Family integration, cooperation, and an optimistic definition of the situation, and marital satisfaction.

For wives, Coping Style II: Maintaining social support, self-esteem, and psychological stability, and marital satisfaction, and Coping Style III: Understanding the health care situation by communicating with other parents and working with a health care team, and marital satisfaction were not found to be positively associated with marital satisfaction in couples raising a child with cerebral palsy. Thus we cannot reject the null hypothesis that for wives there is no relationship between Coping Style II: Maintaining social support, self-esteem, and psychological stability, and marital satisfaction. There is no relationship between Coping Style III: Understanding the health care situation by communicating with other parents and working with a health care team, and marital satisfaction. Bivariate correlations among the variables included in this sample for the CHIP may be found in Table 16 (p. 77).

Research Question IV

It was hypothesized that couples raising a child with cerebral palsy that have a strong family support system will not exhibit higher levels of marital satisfaction than couples with poor familial support. Due to low alpha coefficient reliabilities for both husbands and wives, and the failure of the subscales for sources of family support to hold together, research question IV could not be answered. Refer to Table E-4 in Appendix E for rates endorsed as "not available" for the FSS by husband and wife.

Table 16

Correlations Between Husband Coping Style and Wife Coping Style with Marital Satisfaction as Measured by the RDAS and KMS

	Coping Style I *r*	Coping Style II *r*	Coping Style III *r*
Husband:			
RDAS	.29	-.16	.26
KMS	.26	-.15	.22
Wife:			
RDAS	.55*	-.17	.18
KMS	.55*	-.31	.18

Note. $p < .05$.

Research Question V

It was hypothesized that couples raising a child with cerebral palsy that have a network of social and professional relationships in the community will not exhibit higher levels of marital satisfaction than couples that do not have external support. Due to low Alpha coefficient reliabilities for both husbands and wives, and the failure of the subscales for sources of community support to hold together, research question V could not be answered. Refer to Table E-4 in Appendix E for rates endorsed as "not available" for the FSS by husband and wife.

Research Question VI

It was hypothesized that there is no relationship between the severity of the child's disability and the parent's level of marital satisfaction. Thus, due to the fact that there was no theoretical reason to believe one group would be more alienated than the other, and in order to avoid violating the assumption of non-equal variance, two-tailed *t* tests were conducted to test hypothesis six.

Two-tailed *t* tests indicated that all bivariate correlations between the severity of the child's disability and the parent's level of marital satisfaction were nonsignificant for both husbands and wives. Thus, we cannot reject the null hypothesis that for husbands and wives there is no relationship between the severity of the child's disability and the parent's level of marital satisfaction. Table 17 contains the *t* tests, and mean and standard deviation scores for the severity of the child's disability.

Table 17

Independent Samples t-Test Analysis of Severity of Child's Disability on Marital Satisfaction for Husbands and Wives

Severity	*n*	*M*	*SD*	*t*	*df*	Sig.
Husband RDAS						
Mild/moderate	16	61.13	7.35	.472	26	.641
Severe	12	59.59	9.96	.452	19	.656
Husband KMS						
Mild/moderate	16	17.19	3.02	1.03	26	.313

(*Table 17 continues*)

Severe	12	15.67	4.80	.965	17	.348
Wife RDAS						
Mild/moderate	15	62.73	7.75	.300	26	.767
Severe	13	61.62	11.83	.291	20	.774
Wife KMS						
Mild/moderate	15	17.00	3.59	.846	26	.405
Severe	13	15.46	5.91	.817	19	.424

CHAPTER V

DISCUSSION AND CONCLUSIONS

Summary of Research Study

The purpose of researching the factors that influence marital satisfaction in couples raising a child with cerebral palsy was to identify specific factors that contribute to marital satisfaction in order that parents and those who work with families of children with cerebral palsy may understand the implications of this disability on the marital relationship. Specifically, this study examined couple cohesion and adaptability, individual coping style, and sources of family and community support. By examining these issues, through family systems and social ecological perspectives, factors associated with higher levels of marital satisfaction in couples raising a child with cerebral palsy as well as areas of needed support were identified.

Discussion of Results

Marital Satisfaction

Marital satisfaction is a function of all marriages; thus, it is important to understand the dynamics influencing marital satisfaction in couples in general. Theories of marital satisfaction tend to revolve around the common themes of satisfaction with spouse, satisfaction with marriage, and satisfaction with the marital relationship (Schumm et al., 1985).

Research regarding the impact of raising a child with a disability on marital satisfaction has been found to be sparse, contradictory, and understudied (Crnic et al., 1983; Lyon & Lyon, 1991; Patterson, 1991). Existing research on this subject has concluded the following. First, marital satisfaction may be influenced by the birth of a child with a disability (Seligman & Darling, 1997). Second, in some instances a child with a disability may aggravate latent marital problems while in other instances strengthen marital commitment (Olsen, 1999; Schwab, 1989). Third, many couples can cope successfully with the aid of family and community support (Greeff, 2000). Fourth, marital dissatisfaction may result in divorce and single parenthood (Joesch, 1997).

In this study, the majority of husbands were very satisfied with their marriage, whereas, the majority of wives were somewhat satisfied. As measured by the KMS, both husbands and wives reported being very satisfied with their husband/wife as a spouse, and somewhat satisfied with their relationship with their husband/wife, with one wife commenting in the margin of the questionnaire that "he is not as thoughtful or loving." (Although respondents were not asked to comment on items in the questionnaire, periodically comments were written in the margins. Pertinent comments have been included in the text of this chapter as they illustrate key findings.)

Examining dyadic consensus, (the approximate extent of agreement or disagreement between spouses) by use of the RDAS (Busby et al., 1995), husbands and wives in this sample almost always agreed on religious matters, making major decisions, and career decisions. Both husbands and wives occasionally agreed on demonstrations of affection and sex relations with one wife commenting that "I don't like things." For conventionality, most husbands occasionally agreed with their wife on correct or proper behavior, where as, most wives almost always agreed with their husbands.

For matters of marital fulfillment concerning dyadic satisfaction, the majority of husbands and wives reported that they had rarely considered divorce or separation and rarely regretted that they married. Both husbands and wives reported occasionally quarreling and getting on each other's nerves.

For matters of marital fulfillment with regard to dyadic cohesion (how often specific events occur between spouses), both spouses report occasionally engaging in outside interests together with one wife commenting that, "we stay home a lot." Similarly, husbands and wives reported working together on a project once or twice a month, with two wives commenting that, "raising our children is the biggest project we work on together." Both spouses reported having a stimulating exchange of ideas once or twice a week, and calmly discussing something such as daily occurrences.

One important finding in this study was that the participant's reported levels of marital satisfaction are comparable to parents of typically developing children, as was reported by Kazak and Marvin (1984). In addition, couples in this study reported higher levels of marital satisfaction than was otherwise expected, based on national reports for both the RDAS and KMS (Busby et al., 1995; Schumm et al., 1985).

Couple Cohesion and Adaptability

For this study, couple cohesion and adaptability were found to be significantly and positively correlated with marital satisfaction for both husbands and wives. In particular, both partners reported high levels of support and closeness.

According to Seligman and Darling (1997) and Mirfin-Vetich and associates (1997), cohesion and adaptability are strongly related to functioning and crisis management and can be strong indicators of a couple's abilities to raise a child with a disability. In this study, cohesion was defined as the emotional closeness that couple members have toward one another. Specifically, couple cohesion included the following concepts: emotional bonding, boundaries, coalitions, time, space, friends, decision-making, interests, and recreation.

When cohesion is balanced (separated and connected), couple systems are apt to be most functional. In this sample, some couples scored as separated, but more couples reported being connected more than any other level of cohesion.

In this sample, the separated couple relationships have clearly defined boundaries, with couple members feeling both a sense of closeness and a sense of autonomy. In addition to reporting clearly defined boundaries, the connected couples also report feeling both a sense of emotional closeness and loyalty with an emphasis on spending time together. For couples with balanced levels of cohesion, high levels of marital satisfaction may stem in part from their abilities to maintain both autonomy and togetherness as needed.

When cohesion is unbalanced (disengaged and very connected), couple systems are viewed as less favorable for couple functioning. When cohesion is very low (disengaged), couple members have low levels of attachment and commitment to each other. In this sample, few couples reported being disengaged.

When cohesion is very high (very connected), there is too much agreement within the couple and too little autonomy. It appears from this sample that several couples are very connected. The very connected couples in this study are characterized as over-involved and over protective with an extreme amount of closeness and loyalty. However, Olson (1992) stated that very connected couple types function well as long as both members prefer it that way. Olson noted that this is particularly true for couples belonging to cultural groups whose norms support family behavior at the extremes (i.e., LDS, Orthodox Jewish, and Amish couples). Because most couples in this sample were LDS, being very connected in terms of their cohesion may not have affected their marital satisfaction adversely.

In this study, adaptability was defined as an individual's ability to change in response to a stressful situation. Specifically, adaptability included the following concepts: leadership, negotiation styles, role relationships, and relationship rules. In this study, both husbands and wives reported that they almost always had a good balance of leadership in their marriage, have equal input regarding major family decisions, and shared responsibilities.

When adaptability is balanced (structured and flexible), couple systems are apt to be most functional. In this sample, some couples were flexible and more couples reported being structured.

Structured couple relationships generally have democratic leadership with some negotiation, stable roles with some degree of sharing, few changes to rules, and rules that are firmly enforced. The few flexible relationships in this sample appear to be based on egalitarian leadership, and employed a democratic approach to decision-making and change.

When adaptability is unbalanced (rigid and very flexible), couple systems are viewed as less favorable for couple functioning. When adaptability is very low (rigid), relationships are based on one highly controlling individual who is in charge. In this sample, some couples are rigid. The rigid couples in this sample are characterized as having low levels of coping skills, lacking the ability to adjust in response to a stressful situation, and being limited in negotiation, with strictly defined roles and unchanging rules.

When adaptability is very high (very flexible), there is too much agreement within the couple and too little autonomy. It appears from this sample that the largest percentage of couples scored as very flexible (32%). Despite the fact that very flexible couples generally experience erratic or limited leadership, make impulsive decisions and experience role ambiguity, couple adaptability scores correlated positively with marital satisfaction in study participants.

This finding may be due in part to the linear nature of FACES II scores and their correspondence to couple types. Olson (1992) noted that empirical data suggest that FACES II does not capture the extremely high categories of "very connected" and "very flexible" couples, and that such scores on the adaptability and cohesion dimensions should be reinterpreted as "very connected" and "very flexible."

Individual Coping Style

Theories on family stress and resiliency typically include coping as an active process (Bailey & Smith, 2000), encompassing both the use of existing family resources and the development of new behaviors and resources, which ideally will help to strengthen the family unit and reduce the impact of stressful events and facilitate their recovery. Similarly, Margalit and Ankonina (1991) stated that individual coping style is comprised of cognitions and behaviors used to evaluate stressors and strains and initiate activities, with the aim of decreasing the impact on stressors. Effective coping styles can lessen the negative effects of the stressors of raising a child with a disability and are beneficial to individual and couple functioning.

Coping pattern I: Maintaining Family Interaction, Cooperation, and an Optimistic Definition of the Situation related to marital satisfaction only for wives in this sample. Specifically, this pattern examines ways of strengthening family life and relationships and assesses the parent's outlook on life with a chronically ill child.

Fincham and Linfield (1997) speculated that the relationship between marital satisfaction and coping might be weaker in couples where compassionate, supportive behavior is not displayed routinely; conversely, the better they (the couple) are able to do these things, the higher their marital satisfaction. One could further speculate that coping style I related to the marital satisfaction of wives, but not husbands, due to husband's ability to show greater support to their wives. Further, wives' roles as homemakers and kin keepers may affect their need to maintain family interaction and cooperation and optimism.

Coping pattern II: Maintaining Social Support, Self-Esteem, and Psychological Stability and Coping pattern III: Understanding the Health Care Situation by Communicating with other Parents and Working with a Health Care Team did not relate to marital satisfaction for either husbands or wives in this sample. Specifically, the second coping pattern looks at the parents' efforts to develop relationships with others and engage in activities that enhance feelings of individual identity and self worth. Coping pattern III focuses on the parent's relationship with health care professionals and other parents of chronically ill children.

Theories of social support (Bailey & Skinner, 1999) indicate that it is the family member's relationship to the community and each other that influences self-esteem and network support. Bailey and Smith (2000) indicate that a couples' ability to cope effectively with the stressors and strains associated with raising a child with a disability is influenced by the larger social systems in which they individually and collectively thrive. Essentially, an individual's response to an event and their coping method is derived from a combination of beliefs and experiences.

Family stress and resiliency theories include coping as an active process encompassing both the utilization of family and community resources (Margalit & Ankonina, 1991). Consequently, one would expect mothers and fathers in high stress families to report greater use of coping behaviors and sources of support because this reflects an active effort on their part to manage the conflict and adapt to the situation.

For this study, no relationship for either husbands or wives was found between coping patterns II and III, which deal with sources of community support. One could speculate that sources of community support as a coping behavior were not related to marital satisfaction because of the strong LDS emphasis on first seeking help from family members. Bailey and Smith (2000) have found that couples that cope successfully have strong familial support.

Family and Community Support

According to Carpenter (2000), family support, whether nuclear or extended, is the most ideal form of emotional and practical support. Such support has been found to be a great benefit to couples raising a child with a disability (Trivette & Dunst, 1990). In this study, family support was defined as any person who is oftentimes helpful to parents in terms of raising their child with cerebral palsy.

According to McCubbin and Huang (1989) social and community support can be mediating factors in helping couples to meet the stressful demands of raising a child with a disability. In this study, social and community support were defined as any group or professional that is oftentimes helpful to parents in terms of raising their child with cerebral palsy such as: medical professionals, early intervention programs, support groups, and social policy.

However, low Alpha coefficient reliabilities for both husbands and wives on the FSS subscales meant that research questions IV and V could not be answered. The lack of reliability of the FSS is attributed to the small sample size. In addition, respondents were given the option of selecting "not available" when describing the helpfulness of various sources of support. Both family support and community support experienced high rates of endorsement of "not available" for several items of the FSS. Table 9 (p. 70) shows the internal reliability estimates for the six subscales of the FSS for husbands and wives. Table E-4 in Appendix E shows the rates endorsed as "not available" for the FSS by husband and wife.

Severity of Cerebral Palsy

McCubbin and Huang (1989) posited that the severity of the child's disability, whether mild/moderate, or severe, can have substantial implications for marital satisfaction. However for this study, no relationship was found between the level of the child's disability and marital satisfaction.

One could speculate that the severity of the child's disability was not related to marital satisfaction due to the strong LDS emphasis on supporting family members, especially during times of difficulty. Barlow (1993) noted that in the marriages that seem to function best, husbands and wives enjoy interaction with a well-established support network of family, friends and neighbors. When in need, they can turn to that network for emotional and social means of support.

It is also likely that the lack of a statistically significant relationship between the level of the child's disability and marital satisfaction is indeed the lack of variability in the outcome measure of marital satisfaction. The trends are in the expected direction; with parents of children having severe levels of CP reporting lower levels of marital satisfaction. However, the difference is not large enough to attain statistical significance.

Limitations of the Study

Any conclusions drawn from this study must be qualified by the limitations of the sample and its unique characteristics; namely, small sample size, its voluntary nature, and homogeneity of race and religion among participants.

First, the small sample size and its voluntary nature means that findings cannot be generalized to larger populations of couples with children with cerebral palsy. Non-distressed couples are more likely to volunteer for research than distressed couples, which may explain the high levels of marital satisfaction among the majority of couples in this study. Most couples that were unhappy with their present marriage likely declined to participate. Future studies should be designed to employ a random sample of couples.

Second, homogeneity of race and religion were characteristics of this sample of couples. To attract a more culturally diverse community of couples raising a child with cerebral palsy, future studies need to sample multiple sites in varied locations.

In addition, all couples face stressors, not just those who have a child with cerebral palsy. Not being able to identify how other stressors, such as finances and other children related to the subjects' cohesion and adaptability, individual coping style, and sources of family and community support, as well as their marital satisfaction, is a limitation of this study.

Recommendations for future Research

While it would have been ideal to look at all ages of children with cerebral palsy and marital satisfaction, such an undertaking was not within the scope of this study.

Rather, this study focused on couples raising a child between the ages of 3-17 years. Future studies should be designed to include families from a larger population, in which families with children from diagnosis to adulthood would be better represented. It would also be prudent to examine the developmental stage of the child and its impact, if any, on marital satisfaction.

Future quantitative studies also should focus on additional moderator variables of marital satisfaction in couples raising a child with cerebral palsy, such as understanding and clarification of the characteristics within couples such as commitment to the marriage, communication style, working as a partnership, consideration of each other, and the ability to compromise, that play a major role in buffering the ongoing stressors and strains associated with raising a child with cerebral palsy. One way to accomplish this would be to focus more on gathering information about the nature of existing stresses and strains on the couple system, as well as identifying internal and external sources of support. In particular, efforts to collect information about family and community support, and the amount of involvement families have in community programs should include qualitative studies to identify the circumstances in which such support is helpful to them.

An additional undertaking should be to study why some couples disintegrate while others thrive. Specifically, future investigations should help differentiate between the child, family, and couple characteristics, and other ecological factors that distinguish families that cope well with raising a child with cerebral palsy from those that do not. This would best be accomplished through longitudinal research.

A final recommendation for future research is to see if couples with very connected cohesion levels and very flexible adaptability levels score high in marital satisfaction in a larger study with more diverse population.

Conclusion

Although additional studies are needed to fully understand the implications of childhood disability on the marital relationship, this study suggests raising a child with cerebral palsy may have an impact on couple and family functioning.

As one husband stated in conversation with the student researcher regarding his relationship with his wife, "no event in our entire marriage could rival the despair of that first day. There is no lower depression than the day of being told." Later, he stated that, "raising our son has been our greatest achievement. We have connected in a way I never imagined possible."

Family Systems Theory and the Social Ecology Model suggest that all couples and families are remarkably complex, and that raising a child with a disability adds to that complexity, and that many factors influence their family life. These theories also posit that couples and families change in response to these influences as they progress through the life cycle, and experience their child's developmental milestones.

When a couple faces the challenge of raising a child with cerebral palsy, both members in the dyad must adapt to the extended needs of the child if the marriage is to succeed. Such adaptations often are significant, requiring great sacrifice and individual determination. Couple adaptability and cohesion must continue to evolve as the child matures, because stressors at various periods may affect members of the dyad differently. Much depends on the individual coping skills and sources of support that contribute to the dynamic interactions of the couple at any given point in time (Seligman & Darling, 1997).

This study found that cohesion and adaptability in the form of spousal support played a key role in couples' abilities to successfully maintain their marriages while trying to meet the demands of raising a child with cerebral palsy. Coping by maintaining family interaction, cooperation, and optimism was associated with marital satisfaction among wives. Further study is needed to identify the impact of sources of family and community support on the marital satisfaction of couples raising a child between the ages of 3-17 years with a diagnosis of cerebral palsy.

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APPENDICES

Appendix A: Questionnaire

Sarah L. Stoker
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slstoker@cc.usu.edu

May 1, 2003

Dear Parent,

It has been found in previous studies that raising a child with a disability is truly a compelling, life altering experience, which does affect family functioning, including the marital relationship. The purpose of this study is to look at the impact of selected variables, such as personal coping style, on marital relationships.

The goal of this study is to assist parents and those who work with families with children with disabilities to understand the implications of childhood disability on marriages and families, as well as to identify areas of needed support.

Thank you for participating in this study. By completing and returning this confidential questionnaire you are giving your consent to become a participant in this study. Your participation is voluntary and you may withdraw at anytime without consequence. Participating in this research will not affect any services you may be receiving.

Please do not write your name anywhere on the questionnaire. The questionnaire will have a code number linking you to the study for the purpose of tracking returned surveys. This link will be destroyed after one year. Only the principal investigator and the student researcher will have access to this information, and it will be kept in a locked filing cabinet in a locked room. The information obtained from this research will be reported in aggregate (grouped with all other participants' information) in the form of a publication.

The questionnaire takes about 30 to 40 minutes to complete. Please complete the questionnaires individually and in private. Your participation in this research is considered to be minimal risk, however due to the sensitive nature of this information, if you have concerns about your participation in this research study, please contact Dr. Piercy at 435-797-2387.

Your willingness to be a part of this study is greatly appreciated.

Kathleen W. Piercy, Ph.D.
Principal Investigator

Sarah L. Stoker
Student Researcher

Section I:

Husband/Father Demographic Information

As you fill out the demographic information, please be honest. Mark your answers according to how you feel, not according to what you think the right answer should be. All responses will be kept confidential.

1. What is the month and year of your birth?
Month____________ Year________

2. What is your Ethnicity/Race?

☐ Asian	☐ Caucasian	☐ Pacific Islander
☐ Black	☐ Hispanic	☐ Other _______________

3. What is the highest level of education you have completed?

☐ Some high school	☐ Some college	☐ Master's degree
☐ High school/GED	☐ Associate's degree	☐ Doctorate degree
☐ Technical school	☐ Bachelor's degree	☐ Post Doctorate

4. What is your current occupation?________________________
☐ I work full time (36 or more hours per week)
☐ I work part time (less than 36 hours per week)
☐ I am not currently employed

5. What is your annual income (before taxes)?

☐ Less than $20,000	☐ $40,000 to $59,999	☐ $80,000 to $99,999
☐ $20,000 to $39,999	☐ $60,000 to $79,999	☐ $100,000 or more

6. What is your religious affiliation? ________________________

7. What is the month and year of your wedding anniversary?
Month ____________ Year _______

8. This is my _______ marriage (1st, 2nd, 3rd, etc.).

9. How many children including your child with cerebral palsy reside in your home?____

10. Please indicate the placement, age and gender of your child with cerebral palsy. (If you have more than one child with cerebral palsy, please use the oldest child.)
☐ Oldest child ☐ Middle child ☐ Youngest child

_____ years old ☐ Male ☐ Female

11. My child with CP has been classified as: ☐ Mild ☐ Moderate ☐ Severe

This classification is based on/according to: ____________________________________

____

12. Please respond either "yes" (Y) or "no" (N) to the following questions.

During the past several years, has a physician or school official stated that your child has any of the following?	Y	N	**Do you believe that your child has any of the following?**	Y	N
Attention deficit disorder (ADD or ADHD, hyperactivity)			Attention deficit disorder (ADD or ADHD, hyperactivity)		
Behavioral problems (acting out, aggression)			Behavioral problems (acting out, aggression)		
Cerebral palsy			Cerebral palsy		
Communication problems (speech impaired)			Communication problems (speech impaired)		
Hearing problems			Hearing problems		
Heart condition			Heart condition		
Intellectually disabled (sub average mental ability)			Intellectually disabled (sub average mental ability)		
Learning disability (dyslexia, aphasia, etc.)			Learning disability (dyslexia, aphasia, etc.)		
Orthopedically impaired (gross motor problems)			Orthopedically impaired (gross motor problems)		
Seizures (epilepsy, etc.)			Seizures (epilepsy, etc.)		
Visual problems (glasses, blindness)			Visual problems (glasses, blindness)		
Visual/motor problems (fine motor, clumsiness)			Visual/motor problems (fine motor, clumsiness)		

Please seal this information inside the envelope marked Husband/Father demographic information and proceed to Section II.

Section II.

As you fill out the questionnaire, please be honest. Mark your answers according to how you feel, not according to what you think the right answer should be. All responses will be kept confidential.

Directions: Listed below are people and groups that oftentimes are helpful to parents raising a child with cerebral palsy. Please circle the response that best describes how helpful each of the following has been to you in terms of raising your child during the past 3 to 6 months. If a source of help has not been available during this period of time, circle the NA (not available) response. While you may not find an answer that exactly states your feelings, please mark the closest answer.

Not at All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful	Not Available
1	2	3	4	5	NA

1.	My parents	1	2	3	4	5	NA
2.	My spouse's parents	1	2	3	4	5	NA
3.	My relatives/kin	1	2	3	4	5	NA
4.	My spouse's relatives/kin	1	2	3	4	5	NA
5.	Spouse	1	2	3	4	5	NA
6.	My friends	1	2	3	4	5	NA
7.	My spouse's friends	1	2	3	4	5	NA
8.	My own children	1	2	3	4	5	NA
9.	Other parents	1	2	3	4	5	NA
10.	Co-workers	1	2	3	4	5	NA
11.	Parent groups	1	2	3	4	5	NA
12.	Social groups/clubs	1	2	3	4	5	NA
13.	Church members/minister	1	2	3	4	5	NA
14.	My family or child's physician	1	2	3	4	5	NA
15.	Early childhood intervention program	1	2	3	4	5	NA
16.	School/day-care center	1	2	3	4	5	NA
17.	Professional helpers (social workers, therapists, teachers, etc.)	1	2	3	4	5	NA
18.	Professional agencies (public health, social services, mental health, etc.)	1	2	3	4	5	NA
19.	Other (please specify)	1	2	3	4	5	NA
20.	Other (please specify)	1	2	3	4	5	NA

Directions: Listed below are coping behaviors that oftentimes are helpful to parents raising a child with cerebral palsy. Please circle the response that best describes how helpful each of the following coping behaviors has been to you in terms of raising your child. For coping behaviors that you do not use, please mark A (chose not to use) or B (not possible). While you may not find an answer that exactly states your feelings, please mark the closest answer.

Not Helpful	Minimally Helpful	Moderately Helpful	Extremely Helpful	Chose Not to Use	Not Possible
1	2	3	4	A	B

1.	Talking over personal feelings and concerns with spouse	1	2	3	4	A	B
2.	Engaging in relationships and friendships which help me to feel important and appreciated	1	2	3	4	A	B
3.	Trusting my spouse to help support me and my child(ren)	1	2	3	4	A	B
4.	Sleeping	1	2	3	4	A	B
5.	Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center	1	2	3	4	A	B
6.	Believing that my child(ren) will get better	1	2	3	4	A	B
7.	Working, outside employment	1	2	3	4	A	B
8.	Showing that I am strong	1	2	3	4	A	B
9.	Purchasing gifts for myself and other family members	1	2	3	4	A	B
10.	Talking with other individuals/parents in my same situation	1	2	3	4	A	B
11.	Taking good care of all the medical equipment at home	1	2	3	4	A	B
12.	Eating	1	2	3	4	A	B
13.	Getting other members of the family to help with chores and tasks at home	1	2	3	4	A	B
14.	Getting away by myself	1	2	3	4	A	B
15.	Talking with the doctor about my concerns about my child(ren) with Cerebral Palsy	1	2	3	4	A	B
16.	Believing that the medical center/hospital has my family's best interest in mind	1	2	3	4	A	B
17.	Building close relationships with people	1	2	3	4	A	B
18.	Believing in God	1	2	3	4	A	B
19.	Develop myself as a person	1	2	3	4	A	B
20.	Talking with parents in the same type of situation and learning about their experiences	1	2	3	4	A	B
21.	Doing things together as a family (involving all members of the family)	1	2	3	4	A	B
22.	Investing time and energy in my job	1	2	3	4	A	B
23.	Believing that my child is getting the best medical care possible	1	2	3	4	A	B
24.	Entertaining friends in our home	1	2	3	4	A	B

Not Helpful	Minimally Helpful	Moderately Helpful	Extremely Helpful	Chose Not to Use	Not Possible
1	2	3	4	A	B

25.	Reading about how other persons in my situation handle things	1	2	3	4	A	B
26.	Doing things with family relatives	1	2	3	4	A	B
27.	Becoming more self reliant and independent	1	2	3	4	A	B
28.	Telling myself that I have many things I should be thankful for	1	2	3	4	A	B
29.	Concentrating on hobbies (art, music, jogging, etc.)	1	2	3	4	A	B
30.	Explaining family situation to friends and neighbors so they will understand us	1	2	3	4	A	B
31.	Encouraging my child(ren) with Cerebral Palsy to be more independent	1	2	3	4	A	B
32.	Keeping myself in shape and well groomed	1	2	3	4	A	B
33.	Involvement in social activities (parties, etc.) with friends	1	2	3	4	A	B
34.	Going out with my spouse on a regular basis	1	2	3	4	A	B
35.	Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	1	2	3	4	A	B
36.	Building a closer relationship with my spouse	1	2	3	4	A	B
37.	Allowing myself to get angry	1	2	3	4	A	B
38.	Investing myself in my child(ren)	1	2	3	4	A	B
39.	Talking to someone (not professional counselor/doctor) about how I feel	1	2	3	4	A	B
40.	Reading more about Cerebral Palsy	1	2	3	4	A	B
41.	Trying to maintain family stability	1	2	3	4	A	B
42.	Being able to get away from the home care tasks and responsibilities for some relief	1	2	3	4	A	B
43.	Having my child with Cerebral Palsy seen at the clinic/hospital on a regular basis	1	2	3	4	A	B
44.	Believing that things will always work out	1	2	3	4	A	B
45.	Doing things with my children	1	2	3	4	A	B

Directions: Please circle the response that best describes your feelings regarding your relationship with your spouse. While you may not find an answer that exactly states your feelings, please mark the closest answer.

Almost Never	Once in a While	Sometimes	Frequently	Almost Always
1	2	3	4	5

1.	We are supportive of each other during difficult times	1	2	3	4	5
2.	In our relationship, it is easy for both of us to express our opinion	1	2	3	4	5
3.	It is easier to discuss problems with people outside the marriage than with my spouse	1	2	3	4	5
4.	We each have input regarding major family decisions	1	2	3	4	5
5.	We spend time together when we are home	1	2	3	4	5
6.	We are flexible in how we handle differences	1	2	3	4	5
7.	We do things together	1	2	3	4	5
8.	We discuss problems and feel good about the solutions	1	2	3	4	5
9.	In our marriage, we each go our own way	1	2	3	4	5
10.	We shift household responsibilities between us	1	2	3	4	5
11.	We know each other's close friends	1	2	3	4	5
12.	It is hard to know what the rules are in our relationship	1	2	3	4	5
13.	We consult each other on personal decisions	1	2	3	4	5
14.	We freely say what we want	1	2	3	4	5
15.	We have difficulty thinking of things to do together	1	2	3	4	5
16.	We have a good balance of leadership in our marriage	1	2	3	4	5
17.	We feel very close to each other	1	2	3	4	5
18.	We operate on the principle of fairness in our marriage	1	2	3	4	5
19.	I feel closer to people outside my marriage than to my spouse	1	2	3	4	5
20.	We try new ways of dealing with problems	1	2	3	4	5
21.	I go along with what my spouse decides to do	1	2	3	4	5
22.	In our marriage, we share responsibilities	1	2	3	4	5
23.	We like to spend our free time with each other	1	2	3	4	5
24.	It is difficult to get a rule changed in our relationship	1	2	3	4	5
25.	We avoid each other at home	1	2	3	4	5
26.	When problems arise, we compromise	1	2	3	4	5
27.	We approve of each other's friends	1	2	3	4	5
28.	We are afraid to say what is on our minds	1	2	3	4	5
29.	We tend to do things more separately	1	2	3	4	5
30.	We share interests and hobbies with each other	1	2	3	4	5

Directions: Most couples have disagreements in their marriage. Please circle the response that best describes the approximate extent of agreement or disagreement between you and your spouse for each item on the following list. While you may not find an answer that exactly states your feelings, please mark the closest answer.

Always Disagree	Almost Always Disagree	Frequently Disagree	Occasionally Agree	Almost Always Agree	Always Agree
1	2	3	4	5	6

1.	Religious matters	1	2	3	4	5	6
2.	Demonstrations of affection	1	2	3	4	5	6
3.	Making major decisions	1	2	3	4	5	6
4.	Sex relations	1	2	3	4	5	6
5.	Conventionality (correct or proper behavior)	1	2	3	4	5	6
6.	Career decisions	1	2	3	4	5	6

Directions: Please circle the response that best describes your feelings for each item on the following lists. While you may not find an answer that exactly states your feelings, please mark the closest answer.

Never	Rarely	Occasionally	More Often than Not	Most of the Time	All the Time
1	2	3	4	5	6

7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6
8.	How often do you and your spouse quarrel?	1	2	3	4	5	6
9.	Do you ever regret that you married?	1	2	3	4	5	6
10.	How often do you and your spouse "get on each other's nerves"?	1	2	3	4	5	6

Never	Rarely	Occasionally	Almost Every Day	Every Day
1	2	3	4	5

11.	Do you and your spouse engage in outside interests together?	1	2	3	4	5

Directions: Please circle the response that best describes how often the following events occur between you and your spouse? While you may not find an answer that exactly states your feelings, please mark the closest answer.

Never	Less than Once a Month	Once or Twice a Month	Once or Twice a Week	Once a Day	More Often
1	2	3	4	5	6

12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Work together on a project	1	2	3	4	5	6
14.	Calmly discuss something	1	2	3	4	5	6

Directions: Please circle the response that best describes your feelings for each item on the following list. While you may not find an answer that exactly states your feelings, please mark the closest answer.

Extremely Dissatisfied	Very Dissatisfied	Somewhat Dissatisfied	Mixed	Somewhat Satisfied	Very Satisfied	Extremely Satisfied
1	2	3	4	5	6	7

1.	How satisfied are you with your marriage?	1	2	3	4	5	6	7
2.	How satisfied are you with your husband/wife as a spouse?	1	2	3	4	5	6	7
3.	How satisfied are you with your relationship with your husband/wife?	1	2	3	4	5	6	7

Please seal this information inside the envelope marked Husband/Father questionnaire. Place the two envelopes in the larger envelope and return them to the student researcher.

Thank you for participating in this study.
Your cooperation, honesty, and willingness to share your feelings are greatly appreciated.

Appendix B: Ad, Flyer, Postcard, and Recruitment Letter and Postcard

Are you raising a child with a diagnosis of
Cerebral Palsy
who is between the ages of 3-17 years,
or do you know someone who is?

Utah State University's Department of
Family, Consumer, and Human Development
is conducting a research study
to learn more about
couples' experiences raising a child with
Cerebral Palsy.

If you or someone you know would like more
information about the study,
please call Sarah at 801-599-6973, send an
e-mail to slstoker@cc.usu.edu, or write to
USU FHD, Attn; Kathleen W. Piercy, Ph.D.
Logan, UT 84322-2905.

Are you raising a child with a diagnosis of
Cerebral Palsy
who is between the ages of 3-17 years,
or do you know someone who is?

Utah State University's Department of
Family, Consumer, and Human Development
is conducting a research study
to learn more about
couples' experiences raising a child with
Cerebral Palsy.

If you or someone you know would like more
information about the study,
please call Sarah at 801-599-6973,
send an e-mail to slstoker@cc.usu.edu,
or return the post card below.

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UNITED STATES

BUSINESS REPLY MAIL

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POSTAGE WILL BE PAID BY ADDRESSEE

Utah State University
Family, Consumer, and Human Development
Attn; Kathleen W. Piercy, Ph.D.
Logan, UT 84322-2905

Cerebral Palsy Study at Utah State University

If you or someone you know would like more information about the study, please call Sarah at 801-599-6973, or send an e-mail to slstoker@cc.usu.edu, or return this post card.

Name: ______________________________

Address: ____________________________

City/State/Zip: _______________________

Telephone: __________________________

e-mail: _____________________________

Sarah L. Stoker
USU FHD
Logan, UT 84322-2905
801-599-6973
slstoker@cc.usu.edu

May 1, 2003

Dear Parent,

I am a graduate student at Utah State University in the department of Family, Consumer, and Human Development. I am conducting a research study to learn more couples' experiences raising a child with cerebral palsy. Kathleen W. Piercy, Ph. D., the principal investigator and I are currently seeking participants meeting the following criteria:

- Biological or adoptive parents of a child between the ages of 3-17 years with a diagnosis of cerebral palsy who are willing to individually complete a questionnaire.

The goal of this study is to assist parents and those who work with families with children with disabilities to understand the implications of childhood disability on the family system, especially on the marital relationship, as well as to identify areas of needed support.

The Institutional Review Board (IRB) for the protection of human subjects at Utah State University has reviewed and approved this research project.

I am writing to ask for your assistance in participating in this study. If you or someone you know would like more information about the study, please call Sarah at 801-599-6973, or send an e-mail to slstoker@cc.usu.edu, or return the enclosed post card.

Sincerely,

Kathleen W. Piercy, Ph.D.
Principal Investigator

Sarah L. Stoker
Student Researcher

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Utah State University
Family, Consumer and Human Development
Attn; Kathleen W. Piercy, Ph.D.
Logan, UT 84322-2905

Do you know a couple that might be
willing to participate in this study?

Your Name: ______________________________

Couples Name: ______________________________

Address: ______________________________

City/State/Zip: ______________________________

Telephone: ______________________________

e-mail: ______________________________

Appendix C: Permission to Recruit Letters from Participating Organizations

United Cerebral Palsy of Utah

UCP

Understanding Disabilities,
Creating Opportunities...

February 3, 2003

Ms. Kathy Piercy
Utah State University
Department of Family & Human Development
Logan, UT 84322

Dear Ms. Piercy,

My name is Jessica Petty; I am the Director of Family Services with United Cerebral Palsy of Utah. USU student Ms. Sara Stoker, recently contacted me in regard to a survey she wishes to conduct for a research paper. I have approved this with my supervisor, and invited Ms. Stoker to an upcoming Family Ties meeting where she may conduct this survey with any parent who would like to participate.

We have reviewed the survey and found all of the questions to be acceptable, however we would like confirmation that the Institutional Review Board has approved the survey. If you would please contact me with notice of this approval before February 10 2003, we would be more than happy to accommodate Ms. Stoker, and assist her in every way possible.

Thank you,

Jessica Petty
Director, Family Services
UCP of Utah
266-1805 ext.123

Utah Parent Center

utah parent
information & training center
UPC
for parents of children with special needs

2290 East 4500 South • Suite #110 • Salt Lake City, Utah 84117-4428
(801) 272-1051 • Toll Free in Utah 1-800-468-1160 • Fax (801) 272-8907
Email:upc@inconnect.com / www.utahparentcenter.org

January 23, 2003

To whom it may concern,

Sarah Stoker recently contacted the Utah Parent Center and asked if it would be possible for her to come in and have our parent consultants fill out a survey for her about raising a child with a disability. Since we are a center dedicated to helping parents of children with disabilities get services in the schools and in their communities, we are always looking for a way to educate people on the different issues surrounding raising a child with a disability.

We would be pleased if Sarah Stoker came into our office to conduct her survey to collect information on what it is like to raise a child with a disability. We have quite a variety of disabilities represented here in our office and are more than willing to share the different opportunities and challenges that parents are faced with when raising a child.

We do not have any policies against activities like this as long as we are not asked to give our names or specifics concerning the different cases. If the survey consists of questions that can be answered in a general manner we will be able to participate. We will give a much detail in our answers as possible without violating confidentiality.

Thank you for making the Utah Parent Center a part of your survey efforts. Please do not hesitate to contact us if you have any questions or need any other information.

Sincerely,

Katie Post

Katie Post
Administrative Assistant
Utah Parent Center

Center for Persons with Disabilities at Utah State University

Utah State
UNIVERSITY

COLLEGE OF EDUCATION
Center for Persons with Disabilities
A University Center For Excellence
5800 Old Main Hill
Logan UT 84322-6800
Tel: (435) 797-1981 / 866-284-2821
Fax: (435) 797-3944
http://www.cpd.usu.edu

Fax Note
To Kathy Piercy
Fax# 3845
From S Weston
Phone# 7-0134

April 7, 2003

To whom it may concern:

Sarah Stoker recently contacted the Center for Persons with Disabilities at Utah State University regarding her study on raising a child with cerebral palsy. Sarah has our permission to post recruitment fliers in our facility.

Sarah Rule
Director

Utah Independent Living Center

Utah Independent Living Center
3445 South Main Street
Salt Lake City, UT 84115-4453
800-355-2195

January 29, 2003

Utah State University
Attn: Kathy Piercy, Ph.D.,
Department of Family and Human Development
Logan, UT 84322-2905
435-797-2387

Sarah Stoker has contacted the Utah Independent Living Center asking if it would be possible for her to recruit participants for a research study she is conducting to learn more about couples' experiences raising a child with Cerebral Palsy.

We would be willing to assist Sarah by allowing her to post fliers in our facility with contact information so that those who would like more information about the study will be able to contact her directly.

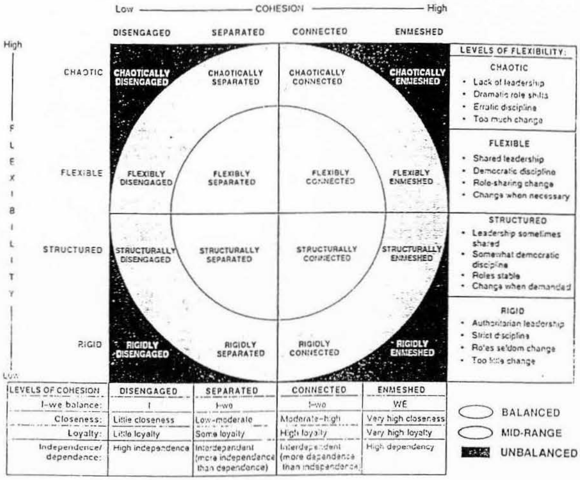
We understand that Sarah will not ask us to provide her with names of parents, and that she will comply with our organizations policies regarding confidentiality.

Sincerely,

Sandy Ratner

Appendix D: Circumplex Model

Circumplex Model



LEVELS OF FLEXIBILITY:

CHAOTIC
- Lack of leadership
- Dramatic role shifts
- Erratic discipline
- Too much change

FLEXIBLE
- Shared leadership
- Democratic discipline
- Role-sharing change
- Change when necessary

STRUCTURED
- Leadership sometimes shared
- Somewhat democratic discipline
- Roles stable
- Change when demanded

RIGID
- Authoritarian leadership
- Strict discipline
- Roles seldom change
- Too little change

LEVELS OF COHESION	DISENGAGED	SEPARATED	CONNECTED	ENMESHED
I-we balance:	I	I-we	I-we	WE
Closeness:	Little closeness	Low-moderate	Moderate-high	Very high closeness
Loyalty:	Little loyalty	Some loyalty	High loyalty	Very high loyalty
Independence/ dependence:	High independence	Interdependent (more independence than dependence)	Interdependent (more dependence than independence)	High dependency

Appendix E: Demographic Information

Table E-1

Demographic Characteristics of Participants by Spouse (N = 56)

Characteristics	Husband/Father *n*	Husband/Father %	Wife/Mother *n*	Wife/Mother %
Age at time of survey (years)				
26-35	6	21.4	10	35.7
36-45	14	50.0	14	50.0
46-55	5	17.8	2	7.1
56-65	0	0	2	7.1
66-75	1	3.5	0	0
No Response	2	7.1	0	0
Highest education level completed				
Some high school	2	7.1	1	3.5
High school/GED	2	7.1	3	10.7
Technical school	1	3.5	6	21.4
Some college	5	17.8	10	35.7
Associate's degree	3	10.7	2	7.1
Bachelor's degree	12	42.8	4	14.2
Master's degree	2	7.1	2	7.1
Doctorate degree	1	3.5	0	0
Occupation				
Entry Level	3	10.7	3	10.7
Skilled Labor	3	10.7	2	7.1
Managerial	3	10.7	0	0
Professional	8	28.5	5	17.8
Exempt-Professional	3	10.7	0	0
Homemaker	0	0	14	50.0
Retired	0	0	1	3.5
No Response	8	28.5	3	10.7
Employment status				
Employed Full Time	26	92.8	3	10.7
Employed Part Time	0	0	9	32.1
Not Employed	2	7.1	16	57.1

(*Table E-1 continues*)

Characteristics	Husband/Father *n*	Husband/Father %	Wife/Mother *n*	Wife/Mother %
Annual income				
Less than $20,000	1	3.5	10	35.7
$20,000 to $39,999	10	35.7	4	14.2
$40,000 to $59,999	13	46.4	0	0
$60,000 to $79,999	2	7.1	0	0
$80,000 to $99,999	2	7.1	0	0
No Income	0	0	14	50.0
Religious affiliation				
Catholic	1	3.5	1	3.5
LDS	23	82.1	24	86.0
Methodist	1	3.5	1	3.5
Native American	1	3.5	1	3.5
None	1	3.5	1	3.5
No Response	1	3.5	0	0

Table E-2

Demographic Characteristics of Participants by Couple (N = 28)

Characteristics	*n*	%
Length of marriage (years)		
1 - 5	1	3.5
6 - 10	5	17.8
11 - 15	11	39.2
16 - 20	4	14.2
21 - 25	5	17.8
26 - 30	0	0
31 - 35	1	3.5
36 - 40	1	3.5
Number of children living in the home		
1	4	14.2
2	4	14.2
3	8	28.5
4	5	17.8
5	4	14.2
6	1	3.5
7	2	7.1
Birth order of child with cerebral palsy		
Oldest	9	32.1
Middle	11	39.2
Youngest	8	28.5

(*Table E-2 continues*)

Characteristics	*n*	%
Age of child with cerebral palsy (years)		
3	3	10.7
4	2	7.1
5	2	7.1
6	5	17.8
7	3	10.7
8	1	3.5
9	2	7.1
10	1	3.5
11	1	3.5
12	2	7.1
13	2	7.1
14	0	0
15	0	0
16	4	14.2
17	0	0

Table E-3

Rates of Endorsement of "Chose Not to Use" and "Not Possible" for the Complete CHIP by Husband and Wife (n=56)

Question	Husband	Wife
Talking over personal feelings/concerns with spouse	1	1
Engaging in relationships and friendships which help me to feel important and appreciated	7	7
Trusting my spouse to help support me and my child(ren)	1	0
Sleeping	5	0
Talking with the medical staff when we visit the medical center	3	1
Believing that my child(ren) will get better	15	11
Working, outside employment	1	13
Showing that I am strong	5	0
Purchasing gifts for myself and other family members	6	8
Talking with other individuals/parents in my same situation	2	5
Taking good care of all the medical equipment at home	9	6
Eating	3	3
Getting other members of the family to help with chores and tasks at home	3	3
Getting away by myself	2	7
Talking with the doctor about my concerns about my child(ren) with cerebral palsy	3	1
Believing that the medical center/hospital has my family's best interest in mind	1	2

(*Table E-3 continues*)

Question	Husband	Wife
Building close relationships with people	8	4
Believing in God	0	0
Develop myself as a person	6	3
Talking with parents in the same type of situation and learning about their experiences	3	4
Doing things together as a family (involving all members of the family)	0	1
Investing time and energy in my job	2	13
Believing that my child is getting the best medical care possible	1	1
Entertaining friends in our home	10	9
Reading about how other persons in my situation handle things	11	4
Doing things with family relatives	2	2
Becoming more self reliant and independent	5	0
Telling myself that I have many things I should be thankful for	0	0
Concentrating on hobbies (art, music, jogging, etc.)	6	6
Explaining family situation to friends and neighbors so they will understand us	2	1
Encouraging my child(ren) with Cerebral Palsy to be more independent	6	4
Keeping myself in shape and well groomed	4	4
Involvement in social activities (parties, etc.) with friends	3	7

(*Table E-3 continues*)

Question	Husband	Wife
Going out with my spouse on a regular basis	6	7
Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	1	3
Building a closer relationship with my spouse	0	1
Allowing myself to get angry	6	3
Investing myself in my child(ren)	0	0
Talking to someone (not professional counselor/doctor) about how I feel	11	4
Reading more about Cerebral Palsy	9	4
Trying to maintain family stability	0	1
Being able to get away from the home care tasks and responsibilities for some relief	3	5
Having my child with Cerebral Palsy seen at the clinic/hospital on a regular basis	2	0
Believing that things will always work out	2	2
Doing things with my children	0	0

Table E-4

Rates Endorsed as "Not Available" for the FSS by Husband and Wife (n=56)

Question	Husband	Wife
My parents	9	6
My spouse's parents	7	8
My relatives/kin	6	5
My spouse's relatives/kin	6	5
Spouse	0	0
My friends	1	3
My spouse's friends	1	10
My own children	2	2
Other parents	10	8
Co-workers	6	13
Parent groups	6	15
Social groups/clubs	10	14
Church members/minister	5	4
My family or child's physician	1	1
Early childhood intervention program	11	10
School/day-care center	1	3
Professional helpers	0	0
Professional agencies	8	14